Technology-Enabled Psychosocial Support for Pediatric Oncology Patients and Caregivers: Case Study of Healthcare and Not-for-profit Resources with Social Media Capabilities

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Technology-Enabled Psychosocial Support for Pediatric Oncology Patients and Caregivers: Case Study of Healthcare and Not-for-profit Resources with Social Media Capabilities

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DEDICATION

In loving memory of my parents and grandparents…

From generation to generation they demonstrated perseverance and taught me how aspiration, knowledge, and resilience can lead to goal achievement.

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ABSTRACT

Due to the acute, life-threatening nature of a pediatric cancer diagnosis, medical attention is paramount. Primary clinical care is usually insufficient to support quality of life for the patient and family in the long term. Psychosocial care should be provided with rigor in parallel but is often a secondary consideration with wide and long-lasting consequences after the acute crisis is in control. This problem may be evident at many levels: medical protocol compliance, behavioral and emotional effects of treatment, family and social impact of continuing care, or financial and economic challenges.

Technology-enabled psychosocial support can contribute to enhancing patient and caregiver quality of life through enabling tools and processes in the health care system. A qualitative study was conducted via literature review, survey, and website analysis. These sources enable presentation of a framework to evaluate cases of pediatric oncology psychosocial support and identification of success and risk factors to technology adoption. The study may be impactful with several applications which provide opportunity for future research including pediatric patient self-advocacy for adult survivorship and family mental health issues. Caregivers may find on-demand support from multiple sources inside and outside their own communities. Adult patients and caregivers might learn from pediatric oncology best practice, particularly people with geographically dispersed families who could use successful technology capabilities.

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My committee, Dr. Bach (Supervisor), Dr. Lohle, Dr. Deeb, Dr. Sheikh, and Dr. Hoffman, each contributed expertise which made the output more impactful than the sum of its parts.

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Steven Belitzky challenged me to continuously change my default lens to solve problems.

Erika Belitzky provided wisdom beyond her years and assistance beyond words.

Support from colleagues, friends, family, and community has strengthened my resolve to see the dissertation process as a step in the path of lifelong learning.

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1 INTRODUCTION

1.1 Research Motivation

This research is motivated by three intersecting concerns: 1) personal, 2) professional, and 3) public benefit. The personal life of this researcher has been significantly impacted by the issues articulated in this work. Firsthand experience for over fifteen years has informed the questions posed, the routes of investigation in the literature, and the reality of navigating the healthcare landscape. The passion that this personal experience brings to the subject cannot be obtained from research alone. As a participant-observer, the richness of understanding when reading, analyzing, and synthesizing provides a compelling obligation to create value from the results.

Similarly, the professional experience of this researcher having over 30 years of corporate information technology practice cannot be overlooked. Having responsibility for keeping the lights on for an organization's technology infrastructure and applications while ensuring reliability and security of data and its supporting platforms does not have the public prestige of a C-level executive position. However, to people who need these services to do their day jobs, the role of middle management ensures the capabilities are available to customers and in turn impacts lives.

Lastly, and more broadly, the World Health Organization (World Health Organization) has calculated that 300,000 children are diagnosed globally with cancer each year. Figure 1 illustrates the publicity this topic is receiving on the world communications stage. The non-profit Cure Childhood Cancer (Cure Childhood Cancer) claims that >50% of childhood cancer survivors live at least 5 years with some chronic health condition. This

translates to 1.5 million impacted children over a decade. The National Pediatric Cancer Foundation (National Pediatric Cancer Foundation) identifies cancer as the number 1 cause of death by disease for children (Figure 2). The not-for-profit Cure Childhood Cancer has research indicating long-term outcomes for pediatric oncology survivors include health conditions (Figure 3).

Figure 1. World Health Organization data (World Health Organization)

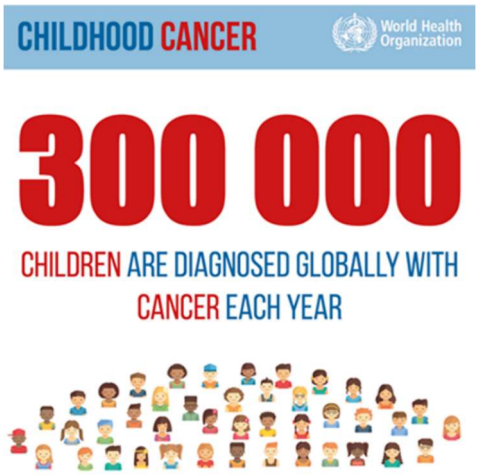


Figure 2. National Pediatric Cancer Foundation statistics (National Pediatric Cancer Foundation)

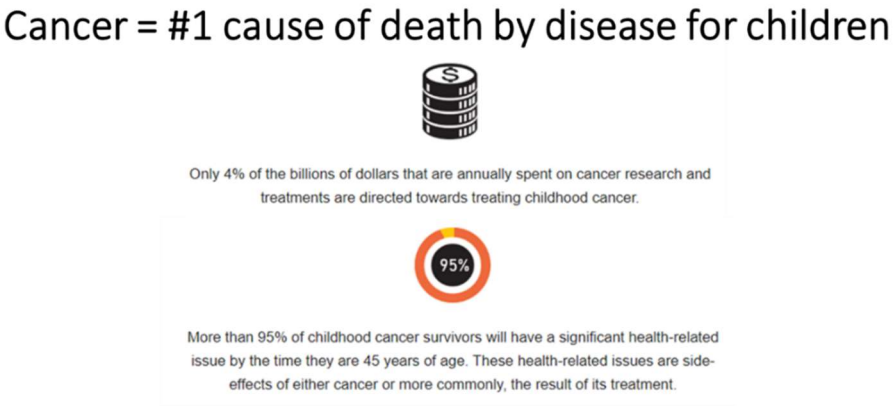
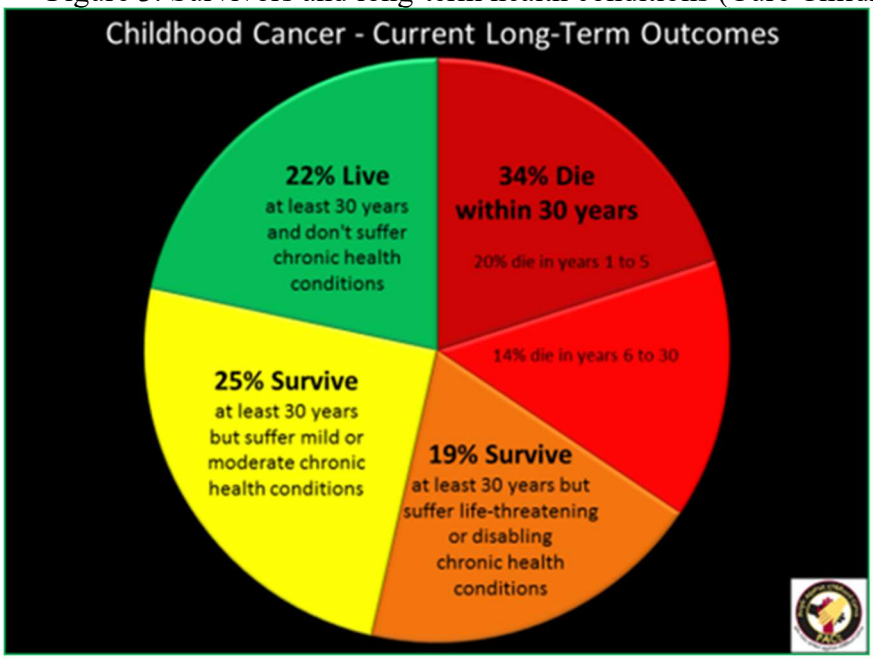


Figure 3. Survivors and long-term health conditions (Cure Childhood Cancer)



1.2 Pediatric Oncology Patients and Caregivers

Survivorship quality of life is influenced by technology-enabled psychosocial support during the onco-care lifecycle. Once a diagnosis is received, the patient may be considered a survivor. Survivorship in this context is the state of being a survivor, whether during or post-treatment. Quality of life refers to one's ability to live in a manner consistent with the personal choices one would or could make had a diagnosis not been present. Technology-enabled psychosocial support is the use of devices, tools, information, and/or applications to help patients and their caregivers have the internal and external resources to cope with adversity.

The Leukemia and Lymphoma Society provides several examples with evidence of the problem (Leukemia and Lymphoma Society). Commonly, medical protocol

compliance might be demonstrated when a patient or caregiver is anxious about a missed a dose of medication. Behavioral and emotional effects of treatment could be exhibited when a child is afraid to go to school after chemotherapy. The family and social impact of continuing care could be long-term due to resigning from employment to be a full-time caregiver. Financial and economic challenges such as fighting an insurance claim and not understanding the system can be exhausting to those unfamiliar with requirements and who did not plan for such unexpected circumstances.

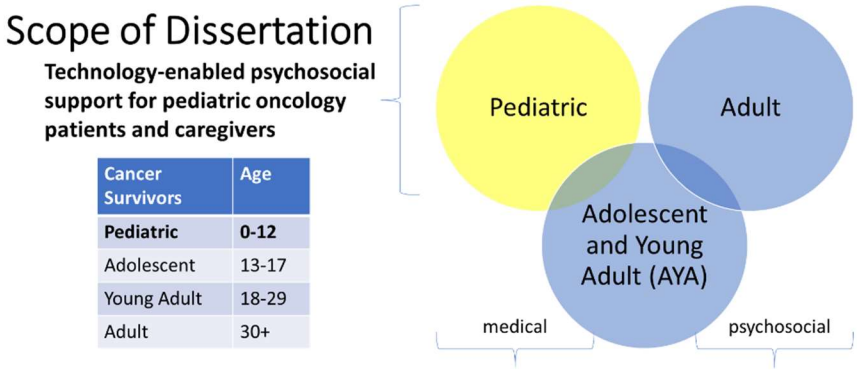
The scope of this dissertation has a focus on the pediatric oncology community. Table 1 lists different types of pediatric cancers with acute lymphoblastic leukemia (ALL) the most common. Figure 4 defines pediatric as children diagnosed from 0-12 years of age and distinguishes this population from adults and the adolescent and young adult (AYA) patients.

Table 1. Types of pediatric cancers (American Cancer Society; Leukemia and Lymphoma Society; Roswell Park Cancer Center)

Pediatric Cancers
Leukemia - Acute Lymphoblastic Leukemia (ALL) is the most common
Brain and spinal cord tumors
Neuroblastoma
Wilms Tumor
Lymphoma (including both Hodgkin and non-Hodgkin)
Neuroblastoma
Rhabdomyosarcoma
Retinoblastoma

Bone cancer (including osteosarcoma and Ewing sarcoma)

Figure 4. Pediatric oncology scope of dissertation (Devine, Viola, Coups, & Wu, 2018)



1.3 Available Resources

Knowledge management systems and patient care systems have traditionally been developed, implemented, and utilized in very different spheres. A patient care system or provider portal is typically institutional in nature, provides historical data on physician or hospital visits and medical tests, with limited interfaces to the comprehensive patient care universe. In contrast, knowledge management systems may be organization based or social based and have information that is publicly available or personal to a selected community. In either case, integrated platform support for both types of systems under a single umbrella interface is not widely available for the pediatric oncology caregiver.

This research aims to understand if broadening knowledge management systems can be enabling for more effective pediatric oncology care practice. Following a review of literature, a survey of pediatric oncology professionals has provided insights on their willingness to use social media and their professional concerns, in part personal liability and patient security. Future research suggestions are provided to enable development of a

reliable, trustworthy, and secure knowledge management platform to support the pediatric oncology community.

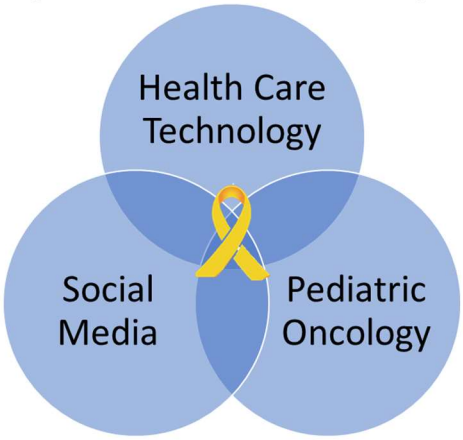
One does not need a cancer diagnosis to appreciate its impact on an individual and that person's ecosystem. Technology managers responsible for knowledge management systems know that process discipline and tool expertise may ease the care burden on patient families and health care professionals who support them. Using pediatric oncology as a case study and researching healthcare systems, the patient experience, and caregiver challenges may provide lessons beyond pediatric oncology to the broader healthcare landscape.

A knowledge management system (KMS) must operate at peak performance when its users rely on information to inform life-threatening decisions. The system must use a tool fit for purpose and free of defects. System requirements include economic and social value, optimal user experience, and no tolerance for harm. Developing the KMS to enable these outcomes, requires process orientation supported by a technology platform developed with strong governance, effective architecture, and appropriate security.

1.4 Social Media Capabilities

Pediatric oncology care, specifically, can be a use case to help us understand these healthcare technology and social media requirements thereby improving the user experience and outcomes for patients (Figure 5). While this use case may at first seem atypical, it serves to demonstrate the utility of wider application for future research.

Figure 5. Use case of intersecting disciplines



The role of social media in healthcare knowledge management systems has been excluded from serious consideration due to lack of secure, reliable information on largely personal, not professional communication platforms. Moreover, information shared on social media is often values driven and unstructured which has traditionally been more difficult to store and mine in corporate-style management information systems. Yet, what may be overlooked by those delivering KMS in an organization is the substance of messaging provided by social media that drives decision-making by families and the need to present this information in a consolidated view for a decision maker under duress.

There is a work in progress void for pediatric oncology caregiving. In the United States, the National Information Center on Health Services Research and Health Care Technology -NICHSR (National Information Center on Health Services Research & Health Care Technology, 2018, 2019, 2020) database tracks research projects and search results demonstrate this gap (Table 2). Managing knowledge in healthcare impacts lives, technology is available to support knowledge management, and social media has power

to transform patient outcomes if leveraged by medical professionals and caregivers. This study aims to reduce the work in process void by developing a conceptual technology framework to integrate professional portals and social media platforms which enable key stakeholders in the caregiving system to communicate with reliable, trustworthy sources thereby improving pediatric oncology patient outcomes.

Table 2. Search Results in HSRProj database (National Information Center on Health Services Research & Health Care Technology, 2018, 2019, 2020)

Keyword Search Results	**17-Jun-2018**	**24-Feb-2019**	**29-Mar-2020**
Pediatric	2314	2441	2562
Oncology	1033	1074	1135
Caregiving	292	305	345
Pediatric Oncology	97	107	113
Pediatric Caregiving	9	10	12
Pediatric Oncology Caregiving	0	1	1

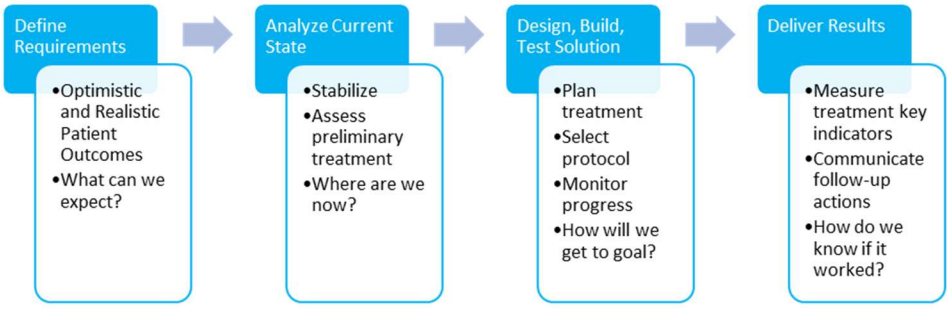
1.5 Technology-enabled Psychosocial Support

The methodology for this research involved three phases following the literature review. These phases were based on well-established methods of innovation process management (Gregory, 1995) and case study research (Yin, 2017). The first phase was a survey (IRB exemption, n = 30), and most participants were oncology nurses (2018). Participants were from Yale (Yale Pediatric Hematology-Oncology), Camp Rising Sun contacts (Camp Rising Sun, 2019), oncology social worker and Facebook personal contacts, and Children's Oncology Camping Association, International (Children's

Oncology Camping Association). The second phase was a systematic assessment of >180 Websites (2019) including US National Institute of Health (NIH) Comprehensive Cancer Care Centers (National Institute of Health) and not-for-profit organizations that service pediatric oncology patients and families. The third phase was a case analysis of 13 selected websites (2020) using structured selection criteria from the prior website assessment.

The discipline of using innovation process management is helpful and can be applicable to the healthcare knowledge management system for pediatric oncology caregiving as it provides a systematic approach to data collection, assessment, and problem solving (Figure 6). The first two steps are defining requirements (the desired patient outcome is remission, treatment should be minimally invasive, adhere to standard protocols as much as possible) and analysis (low blood counts so a transfusion is needed before treatment). This work is followed by design, build, and testing a solution (select the protocol based on lab results and patient examination and history, deliver the chemotherapy plan, check labs weekly to ensure immune system is within control limits). Finally, deliver the product, enable the maintenance plan, and evaluate results (e.g. leukemia treatment protocol includes a bone marrow test, prophylactic antibiotics following the end of chemotherapy, and follow up at a long-term care clinic).

Figure 6: Healthcare Knowledge Management Innovation Process



For engineers and technology managers from a corporate environment and new to healthcare, learning to work via the organization's process is important to solution delivery success. Experienced professionals intuitively follow such process though may not communicate this in a linear fashion. In healthcare, the learning model includes significant mentoring so developing relationships with more senior colleagues can be critical to careers, yet if those same mentors do not understand opportunities to leverage knowledge management benefits via social media while also protecting security and privacy, improvement of healthcare systems may be limited.

Minimizing risk while maximizing benefit of social media for pediatric oncology caregiving demands an engineering approach that requires systematic processing and critical thinking which are also technology management skills. This is especially important due to the population considered. Life or death outcomes are at stake and decisions are based on balancing short term and long-term effects of treatments. One may be surprised that the discipline of pediatric oncology caregiving could have similarities to designing and building a bridge for a civil engineer or launching a spacecraft for NASA.

To the individual and family impacted by a diagnosis, the crisis is real and acute, yet could also be chronic. Where social media weighs in is by providing an opportunity for dialogue, seeking opinions outside one's own circle, and obtaining a range of viewpoints. Social media is an additional communication channel for consideration. In parallel, the patient's medical team provides trusted data and expert opinions. Faith and family tradition also provide a source of influence. Ultimately, the caregiver must make decisions in the patient's "best interest" however that may be defined by the individual.

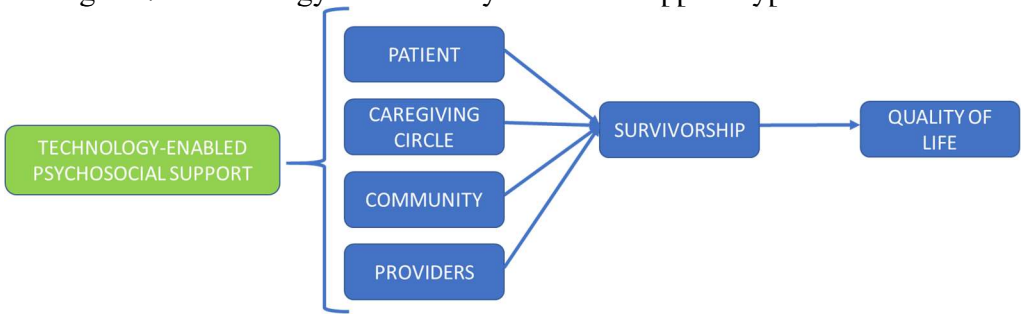
Healthcare leaders, while doing best for the patient, must make decisions in the interest of the public, the organization, work teams, and professional welfare of individuals.

1.6 Research Objectives

The research hypothesis is tested with a pediatric oncology use case. The study seeks to understand how the technology influence may be beneficial or harmful to stakeholders. In this study, survivorship is a series of personal patient decisions beginning at diagnosis and continuing through the patient's lifespan. For children, caregiver(s) makes survivorship decisions on behalf of the patient with medical team support.

On the timeline of survivorship for a child, most of the lifetime for that individual will require obtaining non-medical support resources using technology. The relationship among medical, social, and technology enablers has not been previously studied and may provide a means to address this void (Figure 7). This dissertation including a literature review and other qualitative approaches using primary and secondary data sources identifies best practice examples and shares learnings for future research in leveraging technology for pediatric oncology support services and its wider implications.

Figure 7. Technology-Enabled Psychosocial Support hypothesis research model



2 RESEARCH METHODOLOGY

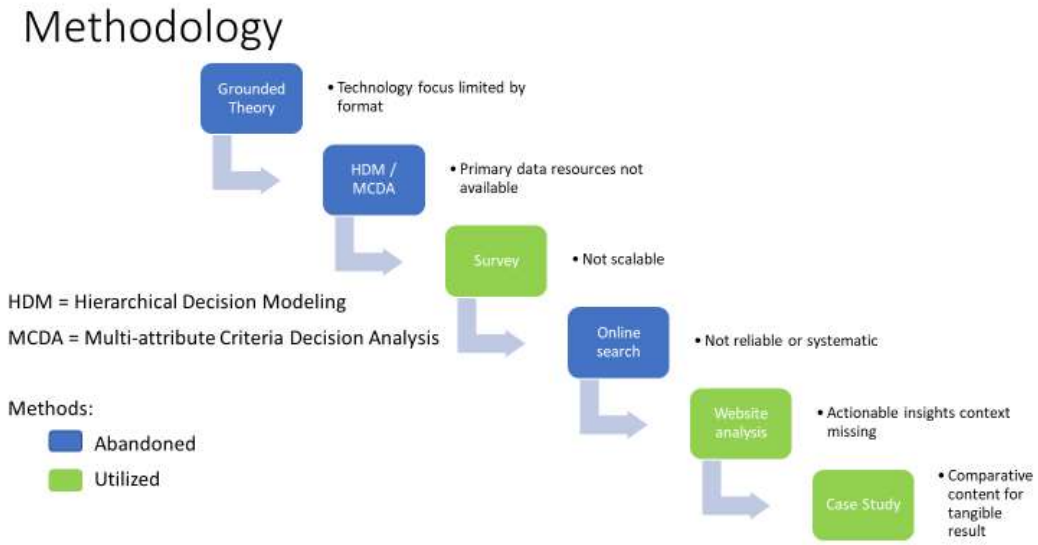
The process to select an appropriate methodology for this research was extensive. Several methods were considered. The first method was grounded theory (Glaser, 2017) whereby reasoning is used to deduce theory from expert opinions. The benefit of this method would have been legitimate use of a small convenience sample size. However, this method was rejected as insufficient to support the rigor required for work in engineering technology management. The next methods investigated were Hierarchical Decision Modelling (HDM) and Multi Criteria Decision Analysis (MCDA) (References). These methods were rejected due to accessibility of primary sources to provide ratings for criteria that would answer the research questions. While Institutional Research Board (IRB) approval for such work could have been navigated, recruitment of participants in sufficient number to obtain valid results was unlikely.

To obtain valid results, the next method considered was a survey to provide some descriptive statistical value (Akard, Wray, & Gilmer, 2015; Doherty, Miller-Sonet, Gardner, & Epstein, 2019; Pfleeger & Kitchenham, 2001; Valdez et al., 2014). The benefit expected was data that identified strengths, weaknesses, opportunities, and threats to social media use as a knowledge management tool for psychosocial support in pediatric oncology. A pilot survey did not yield results that would scale, so an alternate methodology based on secondary data was sought. Finding secondary data required the researcher be curious as a caregiver would be looking to find information and support online. (Khan, Uddin, & Islam, 2019)

Available data was identified from medical institutions, government sources of funding, and not-for-profit support services. Institution websites proved to have such secondary data publicly available. Once a substantial dataset was collected and analyzed, there was a roadblock on the depth of this data while maintaining respect for privacy and security concerns.

The case study method from the perspective of healthcare and not-for-profit institutions was identified to address these issues with reliable, public data to answer the research questions. The topic of technology-enabled psychosocial support for oncology framed from the literature review was appropriate for the case study method because there was data to answer the research questions available without using patient or caregiver data. The journey to select this methodology is illustrated in Figure 8.

Figure 8. Research Methodology



A mixed methods qualitative approach was applied to this dissertation research. The next sections describe each of the methods utilized, why it was an appropriate choice, benefits, and limitations. Considering the research was conducted in phases each with data collection from a different target group of people or organizations, the research method should be considered with respect to the data collection method for each iterative phase. The iterations included Participant-Observer (patient/caregiver focus, limited professional input), Survey of Practitioners (oncologists, nurses, social workers), Organization Website Assessment (hospital and social service providers), and Social Media Case Study (medical vs not-for-profit focus). Each method may apply to one or more phases.

2.1 Grounded Theory

Grounded theory method uses inductive and deductive thinking to generate theory systematically. Hypotheses are formulated based on conceptual ideas with data collected through qualitative methods such as documents and interviews (Glaser, 2017). Developing theory about phenomena of interest is relevant to the researcher's personal experience and serves as the purpose of the grounded theory studied.

Grounded theory was selected for this dissertation due to the interdisciplinary nature of the subject and the researcher's unique experiences, personal and professional network, and access to secondary data sources for obtaining information from reliable documents or contacts. This network is important due to privacy and security concerns about social media and the internet, particularly with respect to health information of children and how it might be used in an uncertain future. Iteratively coding data,

customizing the coding, and building categories of data are activities in grounded theory research.

This dissertation explains how that work has been done to progress from an idea through multiple models and landing on a conceptual model that will serve as the basis for a future research program. In grounded theory research data sampling, data analysis, and theory development are not a linear sequence. These steps are repeated until new data does not change the theory proposed. Elements of grounded theory were used in the literature review, stakeholder conversations, survey development and data collection, and website identification and assessment.

Grounded theory has been criticized for reliance on empirical data with a participant-observer researcher. The criticism is overcome in this dissertation by including empirical data as background in support of the problem, but not full reliance for theory justification. Some grounded theory completely ignores existing theories. This dissertation does not overlook theory based on the elements of the technology acceptance models informing the work. Grounded theory in its original form relied on quantitative coding and has more recently moved more toward qualitative work on the spectrum of methodology (Glaser, 2017).

2.2 Ethnography

Ethnography is a qualitative research method which is not performed in a controlled research setting. As an ethnographer, this researcher studied people – cancer survivors, caregivers, medical professionals – and the organizations to which they affiliated. Ethnography in a somewhat novel way can be applied to the internet in

websites and the social media applications and tools these stakeholders use. This application of ethnography method is appropriate to study psychosocial support without risk of harm, invasion of privacy, or breach of confidentiality (Creswell, 2013).

In contrast to the caveman in a cave or the animals in an African jungle, the real life environment studied is the use of internet websites and social media applications, with Facebook as one of the most common examples from the data (Menefee, Thompson, Guterbock, Williams, & Valdez, 2016). Applicable to technology in the field of usability and technology adoption, ethnography in combination with other methods and the information technology experience of the researcher has added deeper understanding of the technical design issues facing implementation of future federated data models for unstructured psychosocial data (Greenhalgh, Stramer, et al., 2010). Examples of this data could include posts, blogs, pins, audio support session recordings, video support session recordings, or vlogs. There is complexity in capturing and coding these data sources for research. There is also complexity in making the data available to researchers across institutions and organizations while protecting personal information and ensuring regulatory compliance for personal data.

The longitudinal nature of ethnography is a good fit for the dissertation topic as it has been explored by the researcher personally for over a decade and academically for three years. This would be cost prohibitive without a personally invested researcher.

2.3 Action Research

Action research is conducted during an activity or occupation. This method was well suited to the research focus and the ability of the researcher to work part-time on

academics while concurrently being employed full time in a corporate technology management role and parenting one systems engineer through undergraduate and graduate school and another future medical practitioner through the career decision process.

These experiences bore witness to expectations pediatric cancer survivors, caregivers, siblings, and their entire support network have for quality of life well after the end of treatment. This researcher witnessed three pediatric cancer diagnosis and treatment experiences in immediate and extended family each treated at a different cancer center in North America. This researcher also witnessed several adult cancer experiences in the network of personal and professional contacts. These observations informed the structured approach to data presented in the dissertation, identify differentiating variables for pediatric cancer, and enable research model development, analysis, and conclusions.

This dissertation overcomes the inherent disadvantage of action research in education. where an education action researcher only applies learning to one classroom. This dissertation will live in anticipated next steps through future affiliations. These affiliations include action following communication with organizations such as Childhood Cancer Data Initiative (Childhood Cancer Data Initiative) and Momcologist Foundation (Momcologist Foundation). Findings can then be aggregated and distributed to other researchers.

2.4 Case Study

Case study method is an investigation of real-life situations (Crowe et al., 2011). Case studies allow collection of detail not obtained by other research designs and are

useful when large data samples are not available. There are many examples of case study research in healthcare technology (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010; Greenhalgh, Stramer, et al., 2010; Pan Zhi & Pokharel, 2007; Shang-Wei, Wun-Hwa, Chorng-Shyong, Li, & Yun-Wen, 2006).

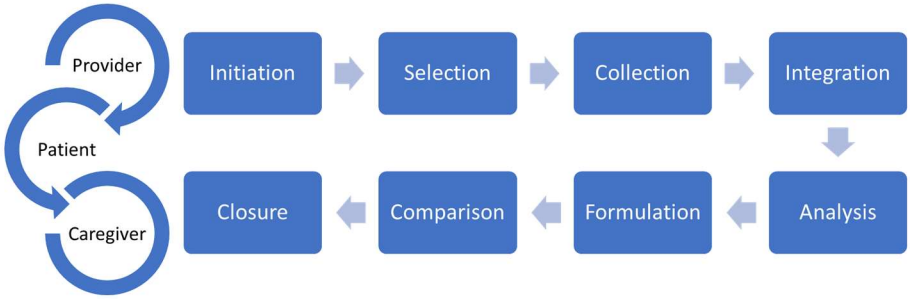
It would be unlikely a researcher would be allowed to attend a support group whether in person or online. Collecting metadata about availability and other characteristics of support resources is a step toward understanding the adoption of technology enabled psychosocial support for pediatric oncology patients and caregivers. Case studies help researchers adapt ideas and create hypotheses which can be tested in future scientific work (Yin, 2017).

One limitation of the case study method is predisposition to bias (R.-F. Chen & Hsiao, 2012). In this dissertation the bias has been identified by revealing researcher affiliations and experience and by explaining the systematic process of case selection and the unbiased evaluation technique to record data in the final phase of work. This dissertation follows best practice for case study methodology by stating which information is obtained informally and which is systematic whether through an IRB reviewed survey obtaining an exemption, a coded website assessment, or a comparative analysis of social media services available through healthcare and not-for-profit websites.

There is a long established process for using case study research to build theory (Eisenhardt, 1989; Ravenswood, 2011) which can be applied to blend the engineering discipline of innovation process management with the reality of providing effective healthcare services. The Eisenhardt (1989) model has been adapted (Figure 9) to apply

this technology management use case by including the relationships between the patient, provider, and caregiver in the healthcare journey for pediatric oncology caregiving.

Figure 9. Case study process adaptation (Eisenhardt, 1989)



The first step in the adapted process (Eisenhardt, 1989) is Initiation whereby the researcher defines research question(s) to focus effort. For this dissertation, the initial question was "How do people, process, and technical factors influence managing technology in organizations?" Next, in Selection, the specified population is defined to constrain the research question(s). For this work it was "How do pediatric oncology patients and caregivers use technology provided by healthcare organizations to obtain psycho-social support?" Prior to collecting data, an initial framework was envisioned that would be used to iteratively assess data obtained. To continue Collection is the next step which involves action to leverage instruments and protocols to collect data. For this dissertation, evidence from multiple tools was planned to include survey of psycho-social professionals, review of care center website offerings, and study of public patient and caregiver social media use.

Following the data effort, Integration is required. This is when the researcher iteratively collects and analyzes data while considering existing models in the literature.

For this dissertation survey learnings aligned with website data but differed from publicly examples of patient and caregiver social media usage. Analysis continues within and across cases, and consideration of alternative models to explain data can result in including and excluding various models or components from models. In the current work, the Technology Acceptance Model (TAM) and its successors (Marangunić & Granić, 2015; Mohamed, Tawfik, Norton, & Al-Jumeily, 2011; Rauniar, Rawski, Yang, & Johnson, 2014) did not fully explain the integrated data. Figure 8 illustrates the chronology of research activities having discarded TAM in 2019 in favor of the case study approach pursued in 2020.

Figure 10. Multi-year research chronology leading to 2020 case study approach

Formulation as a next step according to Eisenhardt (1989) involves shaping the hypothesis and searching for why to sharpen the theory and build internal validity. Applied to this use case, the convenience, comfort, and community of social media support in times of crisis (and ongoing) may outweigh the significance, safety, and security of sole reliance on medical/organization referred providers (and not or). To further explore validity, Comparison is needed. This is where the research must contrast

conflicting and similar literature to build validity and generalizability. Work to consider various models of knowledge management (Ford & Mason, 2013a; Gold, Malhotra, & Segars, 2001; Hemsley & Mason, 2013; Hislop, 2013) and cases in healthcare more broadly (pediatric and adult illnesses and conditions other than oncology) will be explored. Closure brings end to the theory development process when iterative effort yields little improvement in the results. To bring closure to the dissertation work, the model articulates the derived factors which affect adoption of social media for psycho-social support (Abrams, Muriel, & Wiener, 2016; Clauser, Wagner, Aiello Bowles, Tuzzio, & Greene, 2011; Doherty et al., 2019; Dongen-Melman & Sanders-Woudstra, 1986; Kennedy & Hulbert-Williams, 2015) as indicated by patients, caregivers, providers, and others in the community of care.

Table 3. Case Study Report Criteria (Crowe et al., 2011)

Stake's checklist for assessing the quality of a case study report
1. Is this report easy to read?
2. Does it fit together, each sentence contributing to the whole?
3. Does this report have a conceptual structure (i.e. themes or issues)?
4. Are its issues developed in a series and scholarly way?
5. Is the case adequately defined?
6. Is there a sense of story to the presentation?
7. Is the reader provided some vicarious experience?
8. Have quotations been used effectively?
9. Are headings, figures, artefacts, appendices, indexes effectively used?
10. Was it edited well, then again with a last-minute polish?
11. Has the writer made sound assertions, neither over- or under-interpreting?
12. Has adequate attention been paid to various contexts?
13. Were sufficient raw data presented?
14. Were data sources well chosen and in sufficient number?

15. Do observations and interpretations appear to have been triangulated?
16. Is the role and point of view of the researcher nicely apparent?
17. Is the nature of the intended audience apparent?
18. Is empathy shown for all sides?
19. Are personal intentions examined?
20. Does it appear individuals were put at risk?

3 LITERATURE REVIEW

With any knowledge management system, whether it be for archival or decision-making purposes, capture of wisdom for benefit of the system user, might be one measure of success. In the view of Ackoff (1989), wisdom represents a measure of effectiveness and requires values and judgement in contrast to information, knowledge, and understanding as measures of efficiency and more easily captured in a computer system. The impersonal nature of the knowledge management system historically has distinguished man from machine (Ackoff, 1989); however, with social media today, we approach a new intersection of human and machine which does allow the system to convey non-structured content representing values. While the influence of culture on outcomes with use of knowledge management technologies has been widely investigated, few studies have demonstrated how this influence is manifested (Alavi, Kayworth, & Leidner, 2005). Health care decision-making, and pediatric oncology caregiving specifically, is a niche where the benefits and drawbacks of knowledge management, patient care, and social media can be seen to have intersecting interests and to shed light on wider opportunities for managing technology in health care.

3.1 Digital Healthcare Glossary

Background literature on the adoption of health information technologies has been studied and literature reviews have been published (Behkami & Daim, 2016). There have also been case studies about applications, devices, and the settings where healthcare is delivered (Behkami, 2012). Given the volume of this work, a brief glossary of new

terminology is helpful to understand the jargon. Devine et al. (2018) refer to many of the terms in their work which has been summarized in Table 3.

Table 4. Terminology in Technology-enabled Healthcare Provider Services (Devine et al., 2018)

Name	Description
Electronic Health Record (EHR)	Online storage of patient health records
eHealth	Electronic access to healthcare services
mHealth	Mobile access to healthcare services
Telemedicine	Provider services not requiring in person contact
Provider Portal	System access to healthcare provider
Cancer Rehabilitation	Practice recognizing lifelong care for cancer patients
Value-based Healthcare	Practice to measure quality provider service
Certified electronic health record technology (CEHRT)	Ensures security of electronic health records

3.2 Technology Adoption Applied to Healthcare Consumer Sector

The long-accepted Technology Acceptance Model demonstrated that usefulness and ease of use are factors influencing intention to use technology which predict adoption of technology (Davis & Venkatesh, 1996). Subsequently, they expanded this model to include influencing factors (performance expectancy, effort expectancy, and social influence) and facilitating factors (gender, age, experience, and voluntariness of use). UTAUT (Unified Theory of Acceptance and Use of Technology) has been widely referenced (Venkatesh, Morris, Davis, & Davis, 2003) and was further updated as UTAUT2 to include hedonic motivation, price value, and habit (Chang, 2012). Most recently, personal innovativeness as another influencing factor evolved the model to its current state UTAUT3 (Farooq et al., 2017), and it is useful to view the research model for this dissertation use case through this lens. Table 5 and Figure 11 illustrate the model

evolution and Table 6 provides studies where these models apply in healthcare and consumer sectors.

Table 5. Technology Acceptance Model and successor evolution

Model	Description	Reference
TAM	Usefulness and ease of use are factors influencing intention to use technology which predicts adoption of technology.	Davis, F. D. and V. Venkatesh (1996)
UTAUT	Influencing factors are expanded to performance expectancy, effort expectancy, social influence, and facilitating conditions with gender, age, experience, and voluntariness of use as moderating variables.	Venkatesh, V., et al. (2003).
UTAUT2	UTAUT was updated to include hedonic motivation, price value, and habit.	Chang, A. (2012)
UTAUT3	UTAUT2 was extended by introducing the concept of personal innovativeness as an influencing variable.	Farooq, M. S., et al. (2017).

Figure 11. TAM and UTAUTx evolution variables

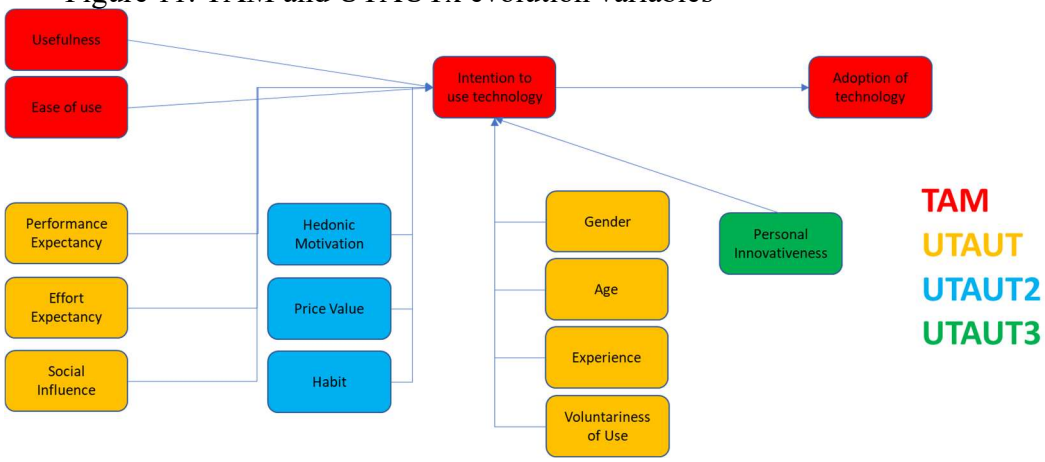


Table 6: TAM / UTAUT models applied in healthcare and consumer sectors

Reference	Model	Function /Technology	Geography	Objective / Results
Straub, Keil, and Brenner (1997)	TAM	Cross-cultural/Email	Japan, Switzerland, United States	Compare results of same instrument for technology acceptance with countries outside of U.S. TAM holds for U.S. and Switzerland, not Japan.

Wu, Tao, and Yang (2007)	UTAUT	Consumer 3G Mobile Communications	Thailand	How to improve customers' willingness to adopt 3G mobile telecommunication services. Factors that significantly influenced the "behavioral intention" include "performance expectancy," "social influence," and "facilitating conditions," while the traditional known "effort expectancy" did not.
Kijsanayotin, Pannarunothai, and Speedie (2009)	UTAUT	Health Information Technology (HIT) in Community Center (CHC)	Thailand	Understand factors that influence health IT adoption in community health centers. CHCs exhibited a high degree of IT acceptance and use.
Pan and Jordan-Marsh (2010)	TAM	Consumer Internet	China	Discuss how various factors intertwine to affect Chinese older adults' decisions to adopt the Internet. The effect of Perceived Ease of Use (PEU) on Internet use intention was also found to be stronger for older seniors than younger seniors.
Putzer and Park (2010)	TAM / DOI	Smartphone in Community Hospitals	United States	Effects of Innovation Factors on Smartphone Adoption among Nurses in Community Hospitals. The innovation characteristics of observability, compatibility, job relevance, internal environment, and external environment were significant predictors of attitude toward using a smartphone.
Orruño, Gagnon, Asua, and Abdeljelil (2011)	TAM	Healthcare / Teledermatology	Spain	Evaluation of teledermatology adoption by health-care professionals using a modified Technology Acceptance Model. TAM was good at predicting physicians' intention to use

				teledermatology. Perception of facilitators to using technology (e.g. infrastructure, training and support) was most important.
I. J. Chen, Yang, Tang, Huang, and Yu (2008)	UTAUT	Consumer Smartphone	Korea	Propose an integrated model of smartphone adoption that incorporates social influences (SIs), perceived technicality, as well as hedonic and utilitarian attitudes into the technology acceptance model. Users' attitudes and their adoption intention are highly influenced by SI and positive self-image.
Ami-Narh and Williams (2012)	TAM / UTAUT	Healthcare /Information and Communication Technology (ICT)	Africa	Revise the generic unified theory of acceptance and use of technology (UTAUT) model to include other constructs and moderators that can be tested for adoption of E-health in health care settings in Africa. Revision of the model to include satisfaction of E-health by users; geographical location of users and the culture of Africans.
F. Aldhaban (2012); Fahad Aldhaban (2015); F. Aldhaban, Daim, and Harmon (2015)	UTAUT	Consumer Smartphone	Saudi Arabia	Determine factors which influence user behavior. Performance expectancy factor, effort expectancy factor, brand influence factor, perceived enjoyment factor and design factor have positive and significant impact on user intentions. Consider human and social factors in the adoption process.
Beglaryan, Petrosyan, and Bunker (2017)	TAM	Hospital Electronic Health Records (EHR)	Armenia	Hospital-based physicians' perspective on using EHR. The proposed model (projected

				collective usefulness; personal innovativeness; patient influence; and resistance to change) explains 85% of variance of behavioral intention to use technology.
Griebel et al. (2017)	TAM / UTAUT	Consumer Smartphone App: eHealth Monitor	Germany, Poland, and Greece	Acceptance by laypersons and medical professionals of the personalized eHealth platform, eHealth Monitor. Laypersons were comfortable with eHealth Monitor, but medical professionals were afraid it could violate their privacy or the privacy of their patients.
B. R. Smith (2017)	UTAUT2 / PMT	Patient/Caregiving Videoconferencing	United States	Assessing patient and caregiver intent to use mobile device videoconferencing for remote mechanically ventilated patient management. Conciseness limited the number of questions that could be asked relative to each sub-construct, prevented confirmatory factor analysis from being used and resulted in using exploratory factor analysis to test construct validity.
Mueller (2017)	UTAUT	Nurse Practitioner eHeallth / mHealth	United States	Family Nurse Practitioners' (FNP) Use of mHealth Apps for Health Promotion with Patients. Patient portal apps were recommended most commonly by FNPs, followed by diet and nutrition apps and fitness apps.
Farooq et al. (2017)	UTAUT2 / UTAUT3	Education/ Lecture Capture System (LCS)	Malaysia	Extend the UTAUT2 by introducing a new variable, namely, PI in the domain of information technology (IT). PIIT, personal innovativeness in

				IT, have a significant and positive influence on acceptance and use of LCS among executive business students.
D'Epiro (2018)	TAM / UTAUT2	Healthcare providers electronic continuing medical education (eCME)	United States	Older generation workers using technology for continuing education. Help individual practitioners and employers more effectively integrate technology into professional learning practices and potentially to influence policy decisions regarding continuing education requirements – both for testing and training and to improve patient care.
Bawack and Kamdjoug (2018)	UTAUT	Healthcare clinician / Healthcare Information Systems (HIS)	Cameroon	Investigating the adequacy of UTAUT1 in determining factors that influence the adoption of HIS by clinicians in developing countries. UTAUT does not predict technology use in developing countries with exception of age. Social influence is a better predictor.
Ladan, Wharrad, and Windle (2018)	TAM / UTAUT	Healthcare professionals	Sub-Saharan Africa (SSA)	Understanding healthcare professionals' adoption and use of technologies in clinical practice: using Q methodology and models of technology acceptance. Findings suggest it is possible to use TAM and UTAUT to develop a comprehensive set of statements. These statements reflect choices that HCPs consider on IT/e-health adoption and use in SSA which can be used in a Q study.

Duncan, Rahim, and Burrell (2018)	TAM / UTAUT	Healthcare / Electronic Health Record (EHR)	United States	Challenges in Healthcare Post-Electronic Medical Record (EMR) Adoption. Despite the mandate's-imposed deadline, 100% adoption did not occur.
Hossain, Quaresma, and Rahman (2019)	UTAUT	Healthcare / Electronic Health Record (EHR)	Bangladesh	Identify the critical factors affecting the physicians' adoption of EHR in healthcare. Policymakers should increase the adoption of the EHR system by developing social strategies to encourage physicians to stimulate each other to use the EHR system and ensuring technical sufficiency, training to facilitate the use of the EHR system.

As it can be observed from Table 6, there are no studies that apply technology adoption models in healthcare to social media. There have been several recent reviews confirming this finding and reinforcing the literature gap (Table 7). The timeliness of this research illustrates interest in pediatric oncology support services given all studies were published in the past three years. When commonalities across these studies are considered, the stakeholder community receives attention. None of this research explores feasibility and desirability of technology across stakeholders to enable a patient-centered holistic platform. Moreover, the relationship between stakeholders and the organizations to which they are affiliated are not consistently considered as a factor of technology adoption.

3.3 Technology Adoption Theories Applied to Social Media

In sum, published frameworks and models do not demonstrate the variables and their relationships to answer the research questions exploring whether social media can be leveraged as a knowledge management tool to provide technology-enabled psychosocial support for pediatric oncology patients and their caregivers. Healthcare technology adoption studies for social media focus on medical providers (Table 7). Studies focus on clinical medicine practice, not psychosocial support.

Table 7. Healthcare technology adoption studies for social media

Study	**Target Population**	**Reference**
Support for Caregivers of Cancer Patients with Technology-Mediated Interventions	Caregivers	Shin, Kang, Noll, and Choi (2018)
Benefits, risks, and best practices of professional social media use in oncology	Medical professionals	Sedrak et al., 2017
Patient-centered communication between adolescent and young adult cancer survivors and their healthcare providers	Healthcare providers	Gorman et al. (2018)
Perspectives of children with cancer, family caregivers, and healthcare professionals about symptoms and factors that may influence symptom reporting	Stakeholders reporting symptoms of children with cancer	Cheng (2018)
Usage of social media by health operators in the pediatric oncohematological setting	Healthcare providers	Clerici et al. (2018)
Technology as it pertains to clinical practice considerations	Healthcare providers	Pennell et al. (2017)
Challenges in Healthcare Post-EMR (Electronic Medical Records) Adoption	Healthcare providers	Duncan et al. (2018)

3.4 Knowledge Management in Patient Care

There is a dichotomy in knowledge management that may not be discussed by patients and caregivers. Knowledge management for the medical community is based on experience, organizational, and research sources to fuel best-practice patient care. The patient/caregiving community increasingly looks beyond the medical provider as a sole source informing decision making. Self, family values, caregivers, friends, clergy as well as online sources such as data based WebMD (WebMD) or social based CaringBridge (Caring Bridge) are examples. Yet in the literature there is little, if any recognition of this complexity faced by the patient/caregiver. This discussion is intended to target the caregiver in pediatric oncology because the diagnosis is life-threatening. The patient is not expected to be capable of self-advocacy hence the need for effective caregiving is acute.

A patient care system can be viewed as an organization with a goal and the resources to achieve this goal via various targeted outcomes. Research in effective knowledge management suggests that capabilities required include technology, structure, culture, and a "knowledge process architecture of acquisition, conversion, application, and protection" (Gold et al., 2001). Grounded theory was used to describe the process for Chinese women gaining acceptance living with breast cancer. As treatment stage progressed, so did acceptance. Researchers developed a model to demonstrate acceptance stages which provided intervention opportunities as each stage. S.-Q. Chen, Liu, Li, and Su (2017) stated that the accepting process included five stages, viz., non-acceptance, passive acceptance, willingness to accept, behavioral acceptance, and transcendence of acceptance. Similarly, there is opportunity to develop a model for use of knowledge

management systems by pediatric oncology caregivers, and perhaps there are commonalities.

In patient care ethics, social media, and medical professionalism, the related literature suggests that there are embedded assumptions in patient care that practice is ethical, and these ethics rules can be explicitly defined (Bradshaw, 1996). Nursing practice teachings have attempted to find moral basis for care from many sources and with many variations, but standard care practices follow Judeo-Christian tradition (Bradshaw, 1996). In contrast to researchers encouraged by the benefits of social media content, there is another view that social media is hazardous for medical professionalism (Greysen, Kind, & Chretien, 2010). A new way of working with patients can be challenging for traditionally trained medical professionals. The impact of online content may not be fully understood by all parties involved in posting and using the information. Content could be reposted in a different context to which it had been intended with the original purpose of the message distorted – intentionally or unintentionally. It is easy for a brief lapse in judgement by any individual to have gross unprofessional, or harmful consequences. As an outcome, that individual could be held accountable and face life changing consequences based on one's online footprint. Given the potential impact to the medical profession, a rise in online professional standards is evolving with employers and other advocacy organizations providing leadership to promote the best use of social media while casting a wide net of communication regarding the hazards involved in doing so.

This topic can be addressed with communication in teams, coordination of care, and social media. Factors that contribute to communication breakdowns in global virtual teams can also apply to families coordinating patient care (Daim et al., 2012). Daim

(2012) stated that trust, interpersonal relations, cultural differences, leadership and technology were variables to explore in the delivery of care which aims for positive patient outcomes. Family members may not be co-located, provider availability can be asynchronous, and patient condition may be frequently changing, thus communication breakdown is inevitable.

Caregivers can feel tension in their responsibilities at many levels. One study defined three levels of tension between knowledge management and social media: macro – (organizational), meso – (group), and micro – (individual). While the study applied to organizational leaders, the factors of roles, ownership, control, and value (Ford & Mason, 2013b) may be relevant to understanding how social media has changed knowledge management efforts and how knowledge management practice has embraced social media.

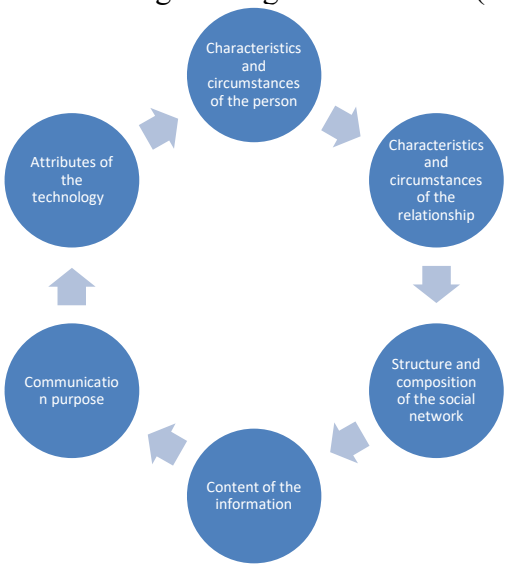
Social media challenges rules in the discipline of enterprise knowledge management (KM). Conceptual foundations of KM models are stretched by the new tools of social media and change how people work and organize (Hemsley & Mason, 2013). Rather than thinking about knowledge management as a capability within an organization which has interfaces to external information providers, the conceptual model evolves to that of a knowledge ecosystem (KE) with much more fluid interfaces and information shared widely (Hemsley & Mason, 2013).

Traditional knowledge management has been top-down in practice. Social media has offered interaction and collaboration with a bottom-up approach and more of a personal orientation. Razmerita, Kirchner, and Nabeth (2014) sought to understand if social media can provide synergy between the two approaches and whether the competition between

the models could be leveraged effectively to reinforce KM overall objectives. Findings were positive and led to a framework classifying social software into four categories based on interaction and control of both the individual and the organization (Razmerita et al., 2014). As relates to pediatric caregiving, the tool (e.g. social media software) would be classified by caregiver as the individual and medical provider as the organization. A decision about whether any tool is fit for purpose would be made by a caregiver or medical practitioner based on the required levels of interaction and control.

Of the many social media tools available, Facebook is one of the most effective albeit controversial platforms also offering a health information knowledge management solution. There is a precedent for research on communicating health information through Facebook (Menefee et al., 2016), and this work characterized patient use of communication within Facebook to understand opportunities for design improvements which would meet preferences for health information needs. Using qualitative interview (N=25) data from a larger mixed methods study focused on diabetes patients in 2014, six themes were identified as rationale for using or not using Facebook features (Figure 12). Results supported having a range of consumer health IT choices to suit rationales of different intersecting values of individuals with the goal of achieving improved health outcomes.

Figure 12. Facebook knowledge management features (Menefee et al., 2016)



Facebook and other web-based methods of communicating with caregivers of pediatric oncology patients have shown promise in recruiting an appropriate population for research (Akard, 2015). Facebook has been leveraged to recruit for research studies relating to consumer health information technology (IT) based on its embedded social structures in the platform (Valdez et al., 2014). Two recruitment strategies were tested: (i) use of direct communication with existing Facebook groups and pages inviting them to a survey link, and (ii) creating a specific group for the study and inviting administrators of targeted related groups to publicize it to their members (indirect approach). Recruiting health-related survey participants via Facebook was feasible if the objective is a small qualitative research sample, but for obtaining large samples needed for quantitative research further investigation would be required (Valdez et al., 2014). Interactions with members of the target population in this study raised ethical concerns regarding boundaries between researchers and participants. The discussions should continue as the

technologies mature and acceptable practices evolve from the business intelligence, technology management, and frameworks perspective.

Business intelligence and analytics has been viewed with three distinct phases of key characteristics each at a different level of maturity (H. Chen, Chiang, & Storey, 2012) Version 1 is a focus on databases and structured data having the most mature implementations. Version 2 is a focus on web-based unstructured content and gaining acceptance. Version 3 is a focus on mobile and sensory-based content in its infancy. One might draw a parallel between these versions of capabilities with the application of them to smart health and well-being. Version 1 being a focus on purely medical information, Version 2 being the addition of tactical and practical environmental considerations such as the economics of healthcare and family caregiving ability, and Version 3 being the holistic well-being of the patient, caregiver, and their extended network to create a recovery system delivering positive outcomes to all participants in the system.

Traditional focus has been on technology management as a linear model of innovation from science to technology, then to production (Gregory, 1995). Gregory proposed a process framework as an alternative tool to describe how manufacturing companies could improve operations and decision making (Gregory, 1995). Benefits of a process framework identified were structure, transparency, stakeholder involvement and satisfaction. The roots of this framework have been applied from strategy and economics disciplines in business. The range of process activities in Gregory's framework cover identification to protection (Gregory, 1995). As applied to knowledge management process in pediatric oncology caregiving this would be analogous to the activities from diagnosis to survivorship care.

Cetindamar, Phaal, and Probert (2009) defined a framework for technology management as shown in Table 8. The researchers find the framework is particularly useful with respect to knowledge management as it not only defines the components in the framework, but it does not limit those components to any definition of order or time. The components are not necessarily sequential, they do not have fixed duration, and they may start and stop multiple times within the overall activity of technology management. While Gudanowska (2017) and predecessors use the technology management framework with respect to an organization, the same components are relevant to a caregiver who creates a virtual organization which has the purpose of caregiving and is distinct in and of itself from the individual whose illness necessitated the need for the creation of the organization in the first place.

Table 8. Technology management framework activities (Cetindamar et al., 2009)

Activities	Description
Identification of technologies	Technologies having a real or potential significance to the enterprise, involving searching, controlling, gathering information and its processing
Selection of technologies	Technologies requiring decision making, preceded by determining priorities accepted by an enterprise at a strategic level, which allows for referring identified technologies to a business strategy
Acquisition	Acquisition of previously selected technologies, decisions concerning the acquisition refer to the choice between the purchase, cooperation or the execution of a technology

Exploitation	Exploitation of technologies to provide financial or other benefits to the enterprise
Protection	Protection of knowledge and experience gathered in the production process
Learning	Learning the knowledge coming from the development and exploitation of technologies, where a strong relation to managing the knowledge in an organization is observed

In Information Technology (IT), clinical care, and cancer support, Hardyman, Hardy, Brodie, and Stephens (2005) provided a forward-thinking comparison between website and telephone helpline for information gathering by people affected by cancer in the UK. In this study, website users requested facts, while helpline users requested opinions or facts about sensitive subjects. Both requesters focused on enquiries for women and/or patients age 50 or older. The study provided early insight that diverse sources can serve a variety of purposes and be complementary.

In 2006, Sittig provided cautious optimism with respect to information technologies which are now a routine part of clinical cancer care (Sittig, 2006). The Internet, real-time clinical decision support systems, population-based systems like big data (Munevar, 2017), gene databases with data mining, wireless monitoring technologies, natural language processing systems, and complex biological system modeling (Sittig, 2006) are all at various stages of maturity, yet have had benefits to create efficiencies and more accurate systems (Sittig & Singh, 2015). Additionally, cumulatively viewed, these technology improvements also present possibilities for unintended, dangerous consequences which must be studied and managed to prepare for future systems development.

Hesse, Hanna, Massett, and Hesse (2010) recognized that deploying health IT is not sufficient to improve delivery of health care services. The authors indicate that the cancer care continuum offers opportunity for a human factors approach that aims at optimizing the balance among health-care users, health-care providers, related technologies, policies and procedures (Hesse et al., 2010). Cognitive support and patient-caregiver engagement create a health-care environment conducive to positive outcomes from diagnosis and treatment to survivorship and end-of-life care. This research is important because it emphasizes meaningful use of health IT, referring to the technology as the tool, and the work refocuses attention on the objective of the process using technology to improve quality of care, and in turn, quality of life.

Focus on information needs in diagnosis and treatment as compared to post-treatment was found in a 2005 study (Rutten, Arora, Bakos, Aziz, & Rowland). Having developed a typology on cancer patients' information needs and the sources of where these needs were met, they found that health professionals provided nearly one-third of the most frequently needed information about stage of disease, treatment options, side effects, and recovery. The work identified a need for future research examining information needs throughout a patient's journey (Rutten et al., 2005).

Given multiple medical providers increasing the complexity of the cancer care systems, related literature offers studies concentrating on coordinated care and psychological support using information technology (IT). The challenges are well documented and there is research to indicate that coordinated care can be lacking which in turn results in insufficient psychosocial support. IT rises as a viable solution that would assist the parties involved decision making processes including patients, caregivers, and

providers. Efficient utilization of IT can enhance communication, coordination, and quality of care (Clauser et al., 2011).

An analogy to disaster relief seems appropriate when a child has a life-threatening illness such as diagnosis with cancer. There is impact not only to the patient and immediate family, but also to the extended family, friends, and community. Gao, Barbier, and Goolsby (2011) discuss advantages and disadvantages of crowdsourcing applications for coordinating disaster relief and provides insight on challenges to address to make these applications useful. While crowdsourcing is typically considered for fundraising, in the case of pediatric illness, it may also include meal delivery to a family, household chores, scheduling visitors, or other needs of the patient and caregiver. In this light, crowdsourcing might be considered as a feature of the knowledge management system.

Kennedy and Hulbert-Williams (2015) report that psychosocial research focuses on the impact on the patient's families, their friends, their formal and informal caregivers, and might even include the reciprocal effects on the patients themselves. While the barriers to conduct psychosocial research can be substantial due to concerns for patient privacy and the need for institutional approvals, both quantitative and qualitative research methods can be effective (Creswell, 2013), individually and jointly (Kennedy & Hulbert-Williams, 2015). Additionally, the researcher may have joint roles, also being a health care provider, or over time becoming emotionally involved with the impact of individual stories on human lives. Precautions can be taken to minimize the influence of these conditions on the research outcomes and ensure researcher support to deliver work output effectively.

Social media has been used for disaster relief in many instances. Nonprofits and media organizations utilized social media effectively to share information about earthquake relief efforts in Haiti; however, analysis of Facebook posts and tweets demonstrated that there was failure to utilize the two-way communication capabilities of these social media tools (Muralidharan, Rasmussen, Patterson, & Shin, 2011). In another study focused on social media use following the January 2010 Haiti earthquake, B. G. Smith (2010) called on public relations practitioners to socially distribute their power to effectively use the tool (e.g. Twitter). Doing so depends on a range of factors such as interactivity, legitimacy, and the user's social stake (B. G. Smith, 2010). This example can be compared to the power of the primary oncologist for a patient sharing via technology with a team of medical and non-medical professionals as well as caregivers, family members, and others. The consequences of shared power in knowledge management when safety is not of concern can clearly be investigated.

Another relevant study investigated emergency knowledge management systems (KMS) in the aftermath of the Haiti earthquake. In this work, the response effort coordinated by three major agencies in tandem with worldwide governments used KMS and included social media for the first time. While the other studies focused on Facebook and Twitter, this one look at wikis and collaborative workspaces(Yates & Paquette, 2011). Both effective and ineffective use of systems was noted with respect to knowledge sharing and decision-making. There were clear lessons learned, strategies for future use offered, and opportunities for ongoing research on use of social media and knowledge management in emergency situations.

3.5 Social Media as a Knowledge Management Tool

The demands on caregivers of pediatric cancer patients are immense and instruments to measure this burden have been documented and reviewed (Tanco et al., 2016). One example of caregiver challenge is the toll of disturbed sleep and sleep quality brought about by guilt and worry (Daniel, 2018). In this study, the multi-year maintenance phase of treatment for acute lymphoblastic leukemia was investigated. In contrast, other research has focused on education needs of newly diagnosed parents/caregivers. If instruction on home care is not understood at point in time of hospital discharge, not only could patient care be affected, but also patients enrolled in clinical trials could affect research results and impact future patients. This effort was initiated by a 2015 symposium and then yielded a literature review, Delphi research study, survey of Children's Oncology Group (COG) institutions, and qualitative study of parental perspectives (Hockenberry and Landier, 2017).

To combat adverse effect of pediatric cancer caregiving, psychosocial screening was found to be acceptable and important to aid in health-related risk factor identification (Lisa et al., 2017). Family caregiver psychosocial status was found to influence reporting of child symptoms (Cheng, 2018). A current review (Shin et al., 2018) indicates a shortage of data regarding helping caregivers of cancer patients by standardizing approach to active information dissemination and implementing support interventions. Multi-component interventions are in their infancy so the need for transdisciplinary research investigators to partner with family caregivers is a relatively unexplored opportunity (Shin et al., 2018). Providing an information solution for caregivers of cancer patients via social media has the advantage of easy accessibility

and no geographic and time barriers (Tang, Chan, So, & Leung, 2014). Tang and colleagues found that web-based interventions could significantly improve psychological distress and enhance caregiver coping skills with recommendation that a comprehensive solution vs. an information dissemination only solution might be more beneficial (Tang et al., 2014).

Social media is in the early proof-of-concept stages with respect to cancer research and there is a promising frontier with respect to data availability, population health, and intervention outcomes (Mina S. Sedrak, Attai, George, Katz, & Markham, 2018). Key to settling this frontier is recognition of social media as an effective platform, understanding appropriate usage, and establishing best practices. Benefits and risks of social media usage are well documented, but the gap identified by this research is in the 'how' for potential applications in pediatric oncology caregiving. The view of social media as a knowledge management system for delivery of business intelligence may be leveraged to rapidly increase the maturity of applications in a healthcare setting. While social media use in healthcare is rising, inherent concerns include protecting privacy, disclosing conflicts of interest and establishing personal and professional identities (Mina S Sedrak et al., 2017).

Facebook offers a platform and caregivers were found to communicate on key themes: (1) documenting the journey, (2) sharing emotional strain, (3) promoting awareness and advocacy, (4) fundraising, (5) mobilizing support, (6) expressing gratitude (Elizabeth A. Gage-Bouchard, LaValley, Mollica, & Beaupin, 2017). The need for knowledge management guidelines and an implementation platform is not limited to the United States. In Italy, the Pediatric Hematology and Oncology

Association created a multidisciplinary working group to develop recommendations which resulted in a consensus statement suggesting an analytical approach rather than restrictive rules (Clerici et al., 2018). With so much opportunity the assessment of information accuracy is important to developing and maintaining trust in social media platforms for information management. In one study with Facebook data only 67% of all cancer information was deemed medically/scientifically accurate indicating social media has potential utility as a cancer-related resource, but also that providers should recommend reliable, evidence-based information sources (Elizabeth A Gage-Bouchard, LaValley, Warunek, Beaupin, & Mollica, 2017).

3.6 Social Media for Patient Care

As the relationship between knowledge management and patient care has been established, and the relationship between social media and knowledge management has been established, it follows that there should be some relationship between social media and patient care. Search results in HSRProj database (National Information Center on Health Services Research & Health Care Technology) demonstrated a gap. Review of frameworks for Technology Management and Knowledge Management further demonstrated that existing models did not fit the problem being studied. Additional deep investigation of the Technology Acceptance Model (TAM) and Unified Theory of Acceptance and Use of Technology (UTAUTx) in its multiple evolutionary versions also did not show promise to explain the model hypothesis. Finally, it was confirmed that the relevance of healthcare technology adoption studies for social media was valid but not alone fit for a complete answer to the research questions.

Over 300 journal articles were identified and assessed. More than 180 websites were reviewed. An IRB approved survey with 30 participants provided data to test an initial hypothesis. More than 20 informal stakeholder discussions over 3 years and attending a national conference webcast with 9 speakers renowned for academic and clinical work in the field have provided inputs to inform this work. The results of the literature review are shared in this section.

Several studies have explored knowledge management in patient care. Tanco et al. (2016) documented and reviewed the immense demands on caregivers of pediatric cancer patients having used instruments to measure caregiver burdens. More recently, Shin et al. (2018) indicated a shortage of data regarding helping caregivers of cancer patients by standardizing approach to active information dissemination and implementing support interventions. Tang et al. (2014) found that providing an information solution for caregivers of cancer patients via social media has the advantage of easy accessibility and no geographic and time barriers. Mina S. Sedrak et al. (2018) learned that while social media use in healthcare is rising, inherent concerns include protecting privacy, disclosing conflicts of interest and establishing personal and professional identities. Elizabeth A. Gage-Bouchard et al. (2017) concluded that Facebook offers a platform and caregivers were found to communicate on key themes: (1) documenting the journey, (2) sharing emotional strain, (3) promoting awareness and advocacy, (4) fundraising, (5) mobilizing support, (6) expressing gratitude. Research in hybrid use of knowledge management systems (KMS) and social media for patient-centric care is in early stages.

There is a dichotomy in knowledge management that may not be discussed by patients and caregivers. Knowledge management for the medical community is based on

experience, organizational, and research sources to fuel best-practice patient care. The patient/caregiving community increasingly looks beyond the medical provider as a sole source informing decision making. Self, family values, caregivers, friends, clergy as well as online sources such as data-based WebMD or social based CaringBridge are examples. In the literature there is little recognition of this complexity faced by the patient/caregiver. This case study concurrently targets the caregiver in pediatric oncology because the diagnosis is life-threatening. The patient is not expected to be capable of self-advocacy hence the need for effective caregiving is acute.

A patient care system can be viewed as an organization with a goal and the resources to achieve this goal via various targeted outcomes. Nearly two decades ago Gold et al. (2001) advised an architecture of acquire, convert, apply, and protect knowledge. Research in effective knowledge management suggests that these capabilities are as relevant today with exponential growth of technology options, variety of available structures, and diversity of cultures served. S.-Q. Chen et al. (2017) more recently used grounded theory to describe the process for Chinese women gaining acceptance living with breast cancer. As treatment stage progressed, so did acceptance, and a model was developed to demonstrate acceptance stages which provided intervention opportunities at each stage. This accepting process included five stages, viz., non-acceptance, passive acceptance, willingness to accept, behavioral acceptance, and transcendence of acceptance. Similarly, there is opportunity to develop a model for use of knowledge management systems by pediatric oncology caregivers, and perhaps there are commonalities.

In patient care ethics, social media, and medical professionalism, the related literature suggests that there are embedded assumptions in patient care that practice is ethical, and these ethics rules can be explicitly defined. Greysen et al. (2010) provide a view that social media is hazardous for medical professionalism in contrast to some researchers encouraged by benefits of social media. A new way of working with patients can be challenging for traditionally trained medical professionals. The impact of online content may not be fully understood by all parties involved in posting and using the information. Content could be reposted in a different context to which it had been intended with the original purpose of the message distorted – intentionally or unintentionally. It is easy for a brief lapse in judgement by any individual to have gross unprofessional, or harmful consequences. As an outcome, that individual could be held accountable and face life changing consequences based on an online footprint. Given potential impact to the medical profession, a rise in online professional standards is evolving with employers and advocacy organizations providing leadership to promote the best use of social media while casting a wide net of communication regarding the hazards involved in doing so.

This topic can be addressed with communication in teams, coordination of care, and social media. Factors that contribute to communication breakdowns in global virtual teams can also apply to families coordinating patient care. Trust, interpersonal relations, cultural differences, leadership, and technology were variables to explore in the delivery of care which aims for positive patient outcomes (Daim et al., 2012). Family members may not be co-located, provider availability can be asynchronous, and patient condition may be frequently changing, thus communication breakdown is inevitable.

Caregivers can feel tension in their responsibilities at many levels. Ford and Mason (2013) defined three levels of tension between knowledge management and social media: macro – (organizational), meso – (group), and micro – (individual). While the study applied to organizational leaders, the factors of roles, ownership, control, and value may be relevant to understanding how social media has changed knowledge management efforts and how knowledge management practice has embraced social media.

Social media challenges the rules in the discipline of enterprise knowledge management (KM) according to Hemsley and Mason (2013). Conceptual foundations of KM models are stretched by the new tools of social media and change how people work and organize. Rather than thinking about knowledge management as a capability within an organization which has interfaces to external information providers, the conceptual model evolves to that of a knowledge ecosystem (KE) with much more fluid interfaces and information shared widely.

Traditional knowledge management has been top-down in practice. Social media has offered interaction and collaboration with a bottom-up approach and more of a personal orientation. Razmerita et al. (2014) sought to understand if social media can provide synergy between the two approaches and whether the competition between the models could be leveraged effectively to reinforce KM overall objectives. They had positive findings and led to a framework classifying social software into four categories based on interaction and control of both the individual and the organization. As relates to pediatric caregiving, the tool (e.g. social media software) would be classified by caregiver as the individual and medical provider as the organization. A decision about

whether any tool is fit for purpose would be made by a caregiver or medical practitioner based on the required levels of interaction and control.

Of the many social media tools available, Facebook is one of the most effective albeit controversial platforms also offering a health information knowledge management solution. Menefee et al. (2016) studied a precedent for research on communicating health information through Facebook, and this work characterized patient use of communication within Facebook to understand opportunities for design improvements which would meet preferences for health information needs. Using qualitative interview (N=25) data from a larger mixed methods study focused on diabetes patients in 2014, six themes were identified as rationale for using or not using Facebook features. Results supported having a range of consumer health IT choices to suit rationales of different intersecting values of individuals with the goal of achieving improved health outcomes.

Akard (2015) believes Facebook and other web-based methods of communicating with caregivers of pediatric oncology patients have shown promise in recruiting an appropriate population for research (Akard et al., 2015). Valdez et al. (2014) explains how Facebook has been leveraged to recruit for research studies relating to consumer health information technology (IT) based on its embedded social structures in the platform. Two recruitment strategies were tested: (i) use of direct communication with existing Facebook groups and pages inviting them to a survey link, and (ii) creating a specific group for the study and inviting administrators of targeted related groups to publicize it to their members (indirect approach). Recruiting health-related survey participants via Facebook was feasible if the objective is a small qualitative research sample, but for obtaining large samples needed for quantitative research further

investigation would be required. Interactions with members of the study target population raised ethical concerns regarding boundaries between researchers and participants. Discussions should continue as the technologies mature and acceptable practices evolve. H. Chen et al. (2012) explain the maturity level development of business intelligence and analytics in three distinct focused phases of key characteristics: (1) Databases and structured data (most mature), (2) Web-based unstructured content (gaining acceptance), and (3) Mobile and sensory-based content (infancy). One might draw a parallel between these versions of capabilities with the application of them to smart health and well-being information in knowledge management systems: (1) Purely medical information (most mature), (2) Tactical and practical environmental considerations such as the economics of healthcare and family caregiving requirements (available with effort), and (3) Holistic well-being of the patient, caregiver, and their extended network (early stages of acceptance). Might such a comprehensive knowledge management system deliver positive outcomes to all participants and stakeholders?

Cetindamar et al. (2009) defined a framework for technology management which does not limit its components to a defined order or timeframe. The six elements of this framework could be sequential but are not required to be so. They include identification of technologies, selection of technologies, acquisition, exploitation, protection, and learning. These components may start and stop multiple times within the overall activity of technology management. While Gudanowska (2017) and predecessors use the technology management framework with respect to an organization, the same components are relevant to a caregiver who creates a virtual organization with the

purpose of caregiving and is distinct in and of itself from the individual whose illness necessitated the need for the creation of the organization in the first place.

Sittig (2006) provided cautious optimism with respect to information technologies which are now routine clinical cancer care. The Internet, real-time clinical decision support systems, population-based systems (i.e. big data), gene databases with data mining, wireless monitoring technologies, natural language processing systems, and complex biological system modelling are all at various stages of maturity, yet have had benefits to create efficiencies and more accurate systems. Additionally, cumulatively viewed, these technology improvements also present possibilities for unintended, dangerous consequences which must be studied and managed to prepare for future systems development.

Hesse et al. (2010) recognized that deploying health IT is not enough to improve delivery of health care services. The authors indicate that the cancer care continuum offers opportunity for a human factor approach that aims at optimizing the balance among health-care users, health-care providers, related technologies, policies and procedures. Cognitive support and patient-caregiver engagement create a health-care environment conducive to positive outcomes from diagnosis and treatment to survivorship and end-of-life care. This research is important because it emphasizes meaningful use of health IT, referring to the technology as the tool, and the work refocuses attention on the objective of the process using technology to improve quality of care, and in turn, quality of life.

Focus on information needs in diagnosis and treatment as compared to post-treatment was found in a study by Rutten et al. (2005). Having developed a typology on cancer patients' information needs and the sources of where these needs were met, they found that health professionals provided nearly one-third of the most frequently needed information about stage of disease, treatment options, side effects, and recovery. The work identified a need for future research examining information needs throughout a patient's journey.

Given multiple medical providers increasing the complexity of the cancer care systems, related literature offers studies concentrating on coordinated care and psychological support using information technology (IT). The challenges are well documented and there is research to indicate that coordinated care can be lacking which in turn results in insufficient psychosocial support. IT rises as a viable solution that would assist the parties involved decision making processes including patients, caregivers, and providers. Clauser et al. (2011) found that efficient utilization of IT can enhance communication, coordination, and quality of care.

An analogy to disaster relief seems appropriate when a child has a life-threatening illness such as diagnosis with cancer. There is impact not only to the patient and immediate family, but also to the extended family, friends, and community. Gao et al. (2011) discusses advantages and disadvantages of crowdsourcing applications for coordinating disaster relief and provides insight on challenges to address to make these applications useful. While crowdsourcing is typically considered for fundraising, in the case of pediatric illness, it may also include meal delivery to a family, household chores,

scheduling visitors, or other needs of the patient and caregiver. In this light, crowdsourcing might be considered as a feature of the knowledge management system.

Kennedy and Hulbert-Williams (2015) report that psychosocial research focuses on the impact on the patient's families, their friends, their formal and informal caregivers, and might even include the reciprocal effects on the patients themselves.

While the barriers to conduct psychosocial research can be substantial due to concerns for patient privacy and the need for institutional approvals, both quantitative and qualitative research methods can be effective (Creswell, 2013), individually and jointly (Kennedy & Hulbert-Williams, 2015). Additionally, the researcher may have joint roles, also being a health care provider, or over time becoming emotionally involved with the impact of individual stories on human lives. Precautions can be taken to minimize the influence of these conditions on the research outcomes and ensure researcher support to deliver work output effectively.

Social media has been used for disaster relief in many instances and is becoming a research data source for quantitative as well as qualitative data. For example, non-profits and media organizations utilized social media effectively to share information about earthquake relief efforts in Haiti. Muralidharan et al. (2011) analyzed Facebook posts and tweets and demonstrated there was failure to utilize two-way communication capabilities of these social media tools. also focused on social media use following the January 2010 Haiti earthquake where public relations practitioners socially distributed their power. To effectively use Twitter, B. G. Smith (2010) found dependency on a range of factors such as interactivity, legitimacy, and the user's social stake. There may be a lesson here regarding the power of a patient's oncologist maintaining a communications monopoly

rather than sharing information via technology with a team of doctors, non-medical professionals, caregivers, family members, and others. Shared power in knowledge management systems warrants exploration particularly when safety is not of concern and benefits may be achieved.

Yates and Paquette (2011) investigated emergency knowledge management systems (KMS) in the aftermath of the Haiti earthquake. Response effort coordinated by three major agencies in tandem with worldwide governments used KMS and included social media for the first time. While other studies focused on Facebook and Twitter, this one looked at wikis and collaborative workspaces. Both effective and ineffective use of systems was noted with respect to knowledge sharing and decision-making. There were clear lessons learned, strategies for future use offered, and opportunities for ongoing research on use of social media and knowledge management in emergency situations.

4 RESEARCH MODEL AND HYPOTHESIS

4.1 Model Development

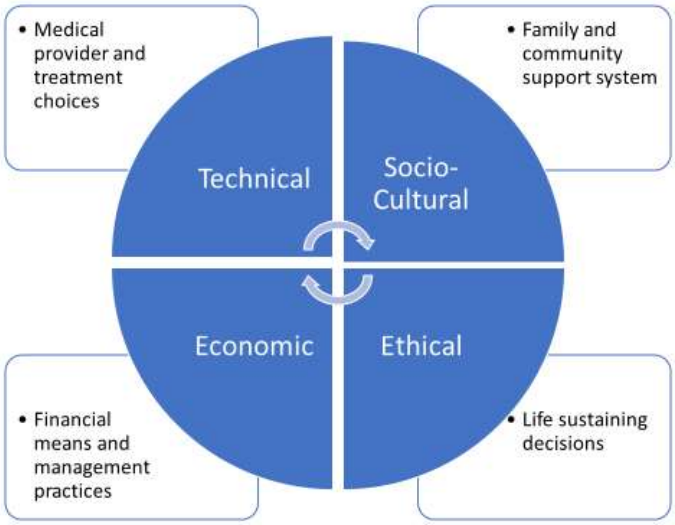
At the start of this research effort and based on the personal researcher experience, ideation of a brainstormed model included four independent variables. The first was medical concerns, the second was economic, the third was social, and the last was values. It was thought that if all these concerns were addressed, then the patient outcome of having a pediatric oncology patient and caregiver not only survive, but also thrive with a high quality of life could be achieved.

4.1.1 Participant-Observer Model Validation

Prior to collecting data, an initial framework was elaborated and documented that was intended to iteratively assess data obtained (Figure 13). The independent variables were further described in a way that could be measured. Medical care was expected to be evaluated by the availability of treatment and choices which led to decreased mortality risk and severity of side effects. This variable was named “Technical”. Financial survival meant that insurance would cover the significant cost of care and that caregiver employment would be secure during the time needed for work-life balance. This variable was named “Economic”. Community would be measured by the number of support services available, their scope, and the duration of service as well as a rating of ability to maintain social relationships during treatment and participate in ‘normal’ activities. This variable was the “Socio-cultural” impact. The final component of the model was perhaps the most important and the least concrete. This dependent variable relates to patient and caregiver abilities to make life sustaining decisions and follow up actions that support

these decisions. This variable was named “Ethical” as an expression that indicates the decisions made reflect the values of the individuals. At this initial phase, there was no reference to using technology as an enabler of psycho-social support.

Figure 13. Initial framework



Using this model for the start of the literature review led to the question of whether social media could be used as a knowledge management tool to influence these variables. It had not been considered if using social media as a technology enabler for general support would provide benefits. As the literature was investigated, it became clear that the one Socio-Cultural variable had the most opportunity through technology-enabled psycho-social support, to be further explored. That is when the survey data collection methodology was employed to learn more.

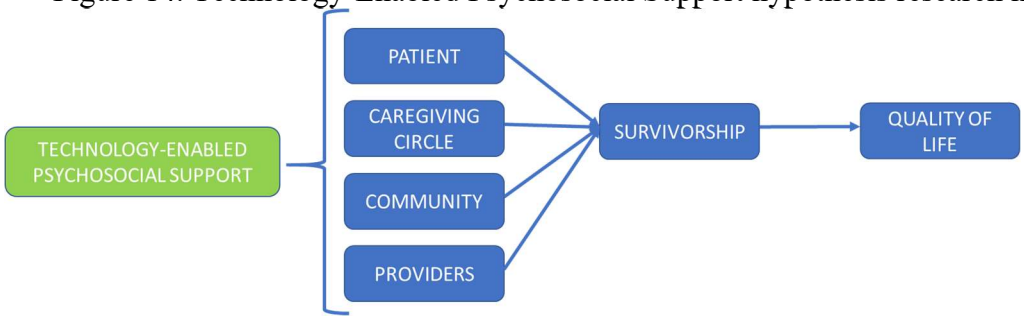
4.1.2 Quality of Life Model

Survey results were anticipated to provide insight that would validate this model. In contrast, the survey marked the first phase of mixed method research enabling a new

model to be developed. A survey sample of 34 responses yielded 30 sufficiently complete to provide value for analysis. In 2018 these preliminary results made clear the medical community in pediatric oncology did not use or plan to use social media extensively for supporting patients and caregivers.

The survey results led to articulation of a new model that extended use of technology-enabled psychosocial support to different stakeholders. The patient, the caregiving circle, the community, and the providers were the dependent variables in this new model (Figure 14). Each of these stakeholders could potentially influence survivorship and in turn influence quality of life for the patient. Data would be required to validate the model and it was recognized that secondary data would be an option to explore due to the sensitivity of patient data and feasibility of data collection.

Figure 14. Technology-Enabled Psychosocial Support hypothesis research model



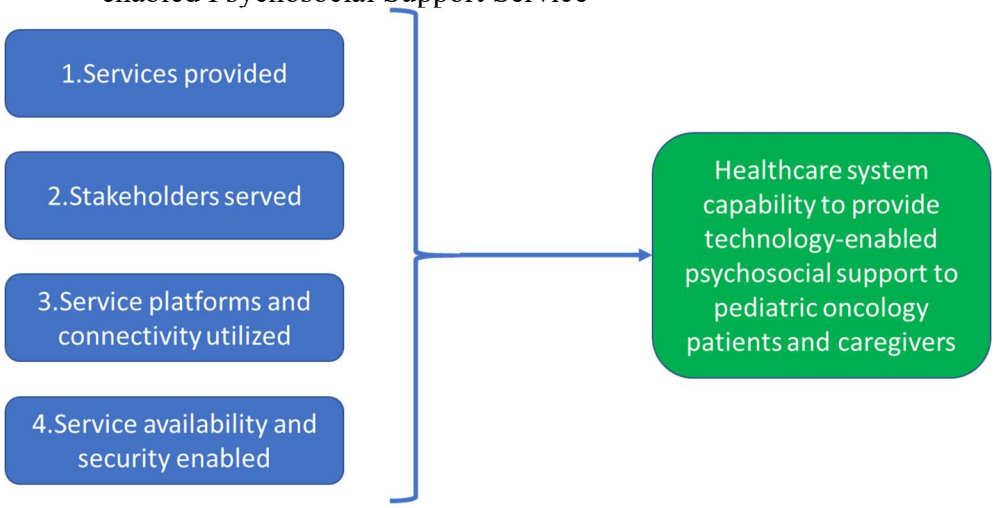
Most pediatric cancer patients in the United States are treated at a hospital or clinic affiliated with National Institute of Health funded cancer centers (Miller et al., 2019). Since this list of centers as well as their website links were publicly available, the model could be tested from data based on services publicized on the websites. This data could be collected and stored in an Excel database file and not contain any private information.

After some websites were evaluated, it became clear that support services publicized were often provided with not-for profit organizations, local and national, who affiliated with the hospitals. At that time, not-for-profit organizations were included in the study. Conclusions from the website analysis were presented at the prospectus defense and more clarity was required to demonstrate the validity of the hypothesis that technology-enabled psycho-social support for pediatric oncology patients and caregivers was provided by organizations and that this service influenced patient quality of life .

4.1.3 Organization Capability Model

Following the prospectus defense, the future research plan was to complete this dissertation with several components. Firstly, propose an updated model based on the integrated research conducted (Figure 15). Then identify at least 10 public use cases for technology-enabled support. These would include both medical institutions and not-for-profit organizations which were referenced to systematically conduct secondary data analysis against the model. Aligned with the public dissertation defense, this work will be shared with the Childhood Cancer Data Initiative (CCDI) (Childhood Cancer Data Initiative).

Figure 15. New Conceptual Model for Healthcare Organization Technology-enabled Psychosocial Support Service



Deeper analysis of the website results led to the development of this organization capability conceptual model. Assessment of the cases provided qualitative validation of this model which can next be tested with quantitative techniques.

4.2 Research Hypotheses and Questions

The research hypothesis is "Technology-enabled psychosocial support influences stakeholders who seek not only survivorship, but also quality of life during the onco-care lifecycle". The research questions investigated include: 1) Who are the stakeholders influencing technology use and what are their adoption criteria? 2) What organization enablers can be activated to achieve use case objectives? 3) Are there best practice examples available and what can be learned from them? Stakeholders identified as patient, caregiving circle, community, and providers fit into the proposed model. A review of literature demonstrates a gap in social support needs of children and their caregivers obtaining non-medical support resources using technology.

5 DATA COLLECTION AND RESULTS

5.1 Validation of Research Problem

Preliminary results from initial research were presented and published in several formats. At the March 2017 Northeast Decision Sciences Institute (NEDSI) Annual Conference, "Lemons to Lemonade: Literature Gap Analysis of Knowledge Management Technology Solutions in Parents' Journey with Childhood Cancer" was presented. Subsequently, Decision Making in Technology Management-Can Knowledge Management Systems Enable Pediatric Oncology Caregiving Effectiveness? was a poster presented at the University of Bridgeport 2018 Faculty Research Day. The initial survey results were published in the Engineering Management Review article Coordinating Unlikely Companions? Patient Portals and Social Media (Belitzky, Kongar, & Lohle, 2019).

5.2 Participant-Observer Conversations

Early in this research, a mixed methods qualitative approach was identified as the most comprehensive way to study this problem. Research was conducted in three formal phases. The first phase focused on attitudes of oncology-care providers in the form of an IRB exempt survey with 30 participants. The second phase focused on technology-enabled psychosocial support services using website analysis of healthcare and not-for-profit organizations. The third phase focused on a case study of healthcare provider and not-for-profit organizations which provide support using social media. Concurrently, there was an informal parallel track to provide context to the formal methodology. This

background work included conversations with oncology professionals, parent/caregivers, and pediatric cancer survivors in the personal network of this researcher (Table 9).

Table 9. Conversations with pediatric oncology stakeholders

Stakeholder Role	**Conversation Date**	**Summary of Inputs**
Pediatric Oncologist	3-Mar-2018	Privacy challenges are substantial for data acquisition from patients and caregivers. Suggested use of public data sources.
Parent – Young Adult Patient	18-May-2018	Involvement in fundraising for pediatric cancer organizations provides camaraderie with like-minded parents who understand shared concerns and fears.
Pediatric Lymphoma Survivor	18-May-2018	Pet therapy is a compliment, not a substitute for psychosocial support from professionals.
Oncology Social Worker	29-Jan-2019	Social workers are important team members to help patients and caregivers navigate resources for support services.
Pediatric Oncology Professor and retired Camp Director	5-Feb-2019	Patient/caregiver data will not yield results regarding technology enablers and blockers for psychosocial support. Suggested continued focus on medical providers.
Pediatric Leukemia Survivor	16-Feb-2019	Job application created anxiety to see cancer as a documented disability despite treatment complete over a decade prior.
Parent advocate of pediatric survivor/ not-for-profit founder	17-July-2019	If a healthcare provider does not have resources for support, find partners who will provide this service to improve quality of life for patients and families.

Parent of pediatric survivor who is a now a parent due to caregiver advocacy	26-July-2019	Grateful for support received to preserve fertility prior to treatment resulting in twice becoming a grandparent
Parent – Adolescent Patient	5-Oct-2019	Value of psychotherapy in developing confidence that cancer would not recur.
Pediatric Sarcoma Survivor	5-Oct-2019	Physical therapy also provides psychosocial support and an outlet for sharing not available in an academic setting.
Parent – Brain Tumor Patient	14-May-2020	Running marathons to raise money for research gives hope and shared experiences with others fighting for the same cause.
Parent advocate of deceased pediatric patient	17-July-2020	There are many passionate, qualified professionals willing to volunteer to provide support. Many have lost a child or experienced significant trauma from a child's diagnosis.

5.3 Survey

Given the personal nature of healthcare and the differences between individual and organization perspectives, a purely quantitative study would limit the understanding that qualitative research could add to the context of the problem. Following the literature review, a conference presentation and poster session served to validate the problem statement. The next step was a survey to refine the scope and understand the technology management challenges. A review paper was published with these initial findings (Belitzky et al., 2019). Research effort in parallel continued with several secondary data sources including websites, informal interview conversations, and conference speakers (Appendix J) which provided contributions to an initial conceptual model. It became

clear that to complete this dissertation there was rationale to use a case study approach. Reasons supporting this conclusion were the novelty of research topic, sensitivity of acquiring primary data (i.e. pediatric patients), availability of secondary data, and the absence of sharing secondary data. There were also well-respected precedents to provide guidance in executing the research for a case study (Creswell, 2014; Yin, 2017) illustrating the model based on public data. Further support for this approach was substantiated in ten studies which use case study methodology in healthcare technology research (R.-F. Chen & Hsiao, 2012; Douma, Karsenberg, Hummel, Bueno-de-Mesquita, & van Harten, 2007; Greenhalgh, Hinder, et al., 2010; Greenhalgh, Stramer, et al., 2010; Hu, Chau, & Sheng, 2002; Jensen, Kjærgaard, & Svejvig, 2009; Murray et al., 2011; Oztekin, Pajouh, Delen, & Swim, 2010; Pan Zhi & Pokharel, 2007; Shang-Wei et al., 2006). They supplement Stake's checklist (Appendix G) as confirmation to enable researcher confidence that the quality of data to be assessed could lead to a reliable result.

5.3.1 Survey Objectives

Given the literature review demonstrated opportunity for social media to improve caregiving when presented as a knowledge management platform for information and support services. Widespread understanding of the issues involved and the necessary technology capabilities, including security was limited. Synthesis between the fields of medicine, information technology, and psycho-social care has not been studied and there is opportunity for synchronization in operational modes. Caregivers' lives are challenged when information cannot be found in one place. This creates risk that optimal patient

outcomes for long term quality of life could be compromised. Would the survey results support the literature review findings?

5.3.2 Survey Development

There were five sections of survey questions and the full survey is provided in Appendix C. The sections include the following:

Professional Experience - Ten questions established and understanding of the demographics, roles, and backgrounds that survey participants represented.

Service via technology - Four questions asked how participants used technology to provide service in general.

Social media for psycho-social support - Nine questions specifically explored workplace use of social media technology.

Personal vs. Professional Preferences - Six questions explored personal vs. professional differences in using social media.

Social Media Usage - Two questions asked for a view on social media appropriateness (efficient, effective, reliable, and secure) for sharing various information in professional practice.

5.3.3 IRB Exemption Approval

The initial instrument used to collect data for this study was an Institutional Research Board approved anonymous survey delivered to participants via a link to Survey Monkey. The survey title was Pediatric Oncology and Social Media and its purpose was to understand expert opinions (oncologists and their colleagues) about social media community in pediatric oncology supports use of social media to complement clinical practice, and why or why not? Findings were used to evaluate social media as a knowledge management tool and to consider the value of an integrated system platform to improve lives of caregivers and potentially patient outcomes.

5.3.4 Participant Recruitment

To pilot if survey data would provide value, in September 2018, initial emails were sent to publicly available addresses of Yale Pediatric, Hematology/Oncology section (Yale Pediatric Hematology-Oncology) in Connecticut, US and the survey link was provided. Responses from five initial participants were encouraging to show that further data collection would be warranted. Subsequently, other distribution channels via the PI's network in oncology were used to increase the number of responses with the majority participants through an email communication by the Executive Director of the Children's Oncology Camping Association, International (cocai.org), who forwarded the survey link to leadership of over 130 COCAI member camps. Email and Facebook were used to contact other possible participants who matched criteria for survey completion which include pediatric oncologists, medical, and non-medical professionals who have contact with

pediatric oncology patients and their caregivers. Patients, caregivers, family, and friends of patients were excluded. Survey participants were not compensated, and the survey took less than 10 minutes to complete.

5.3.5 Survey Results

As of March 22, 2019, there were 34 responses to the survey, with 12% from outside the US, namely Canada. The data is also primarily US based professional experience as nearly 80% of participants have no professional experience outside the country. Responses from medical and psycho-social professionals represented over 85% of the participants. Gender of participants was more than 90% female, and overall more than half the responses were from nurses. Non-medical roles included a camp director and one hospital fundraising professional. Participants were experienced in their profession with 67% having more than 5 years of experience and 47% having more than 10 years of experience. These professionals generally work in a hospital (71%), office (12%), or community/clinic (6%) setting. Urban and suburban patients are served by 88% of the respondents.

The next section of the survey was oriented to use of technology for patient contact. Twenty-nine of the thirty-four participants answered yes/no questions regarding using technology for initial and follow-up patient contact with results about evenly balanced. The preferred technology for patient contact was phone (52%), then email (31%); only 2 participants preferred a patient portal. When asked about psycho-social support only 22 participants answered the questions. Professional counsellors, then family and friends were the recommended choices for both patients and caregivers. Despite this

recommendation, only one participant responded no to the question when asked if social media could provide psycho-social support. There was variation in most and least preferred tools for psycho-social support. Most preferred tools according to participants would be a professional hospital or provider portal (50%) followed by interactive video (23%) compared to traditional email, text, website (18%); least preferred tools reported were those used personally such as Facebook, Twitter, and Instagram (86%) or none (9%). In contrast, there was less variation in reasons that most and least preferred tools were selected. Empathy for patient/caregiver convenience, professional best practice, and fear of information misuse were the top three reasons selected for the most preferred tools. Fear of information misuse, security, and professional best practice were the top three reasons selected for the least preferred tools.

When asked if there is a difference between social media and professional portal online discussions as a resource for patient caregiver information, eighteen responded YES, and there was one NO, while 15 participants skipped this question. At this point in the survey, the number of participants who continued to answer questions was nineteen, and they expressed preferences for using email/text for both personal communication and professional communication. Opinions on social media being safe and secure for both personal and professional communication and social media being reliable and effective for sharing facts and opinions were asked. The only definitive response was that no participants said yes to social media being safe and secure for professional communication. Having the choices of yes, no, and maybe might provide a view to participants openness to change in the future.

The final question of the survey achieved responses from only half the participants as it required rating various factors for appropriate social media information sharing on a scale of 1-7, 1 being the least. While not statistically significant, this preliminary data provides some insight as to which factors might be topics for further research. Medical topics (diagnosis, treatment, care plans), administrative topics (appointments), and research received the lowest scores, while social networks and community interactive meetings, and online discussions received higher scores. There was a more even spread of scores regarding other forms of psycho-social support perhaps as camps were not mentioned as a selection and many participants were recruited from the Children's Oncology Camping Association, International.

Answers to the research questions per this survey were insightful, yet incomplete based on results. Medical providers and their organizations have a role influencing the extent to which patients and families use technology to support their psycho-social support needs. Organization policies, security, privacy, legal requirements, and professional licensing are important factors when implementing technology solutions for users. Some organizations have overcome significant challenges to provide technology-enabled psycho-social support services. Who are they and what do they do? The survey data, while not voluminous, provided substantial behavioral insights for more research (Figure 16, Figure 17, Figure 18, Figure 19).

Figure 16. Survey Results – Social Media Viability for Psych-Ssocial support

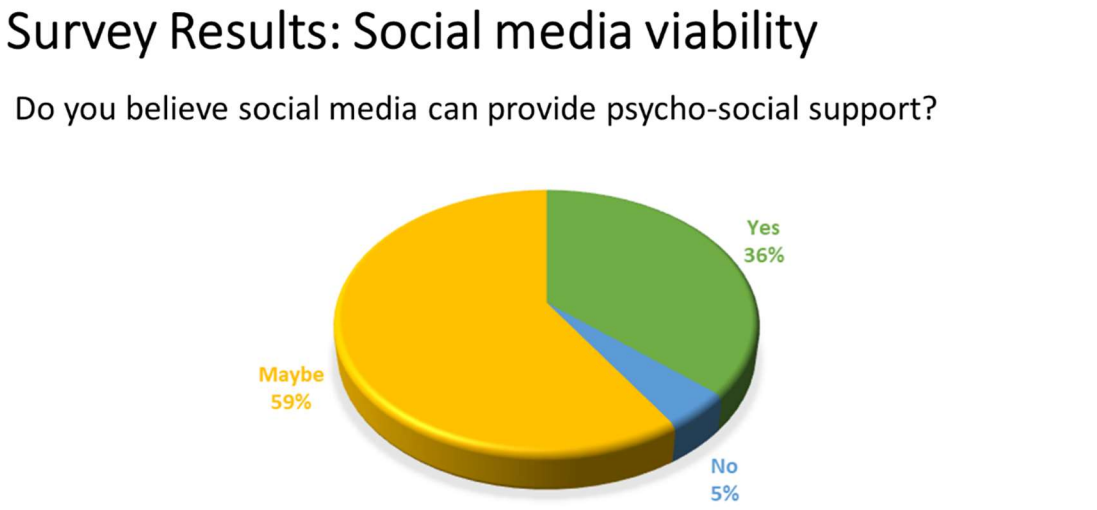


Figure 17. Survey Results – Social Media Tool Preferences for Psych-Ssocial support

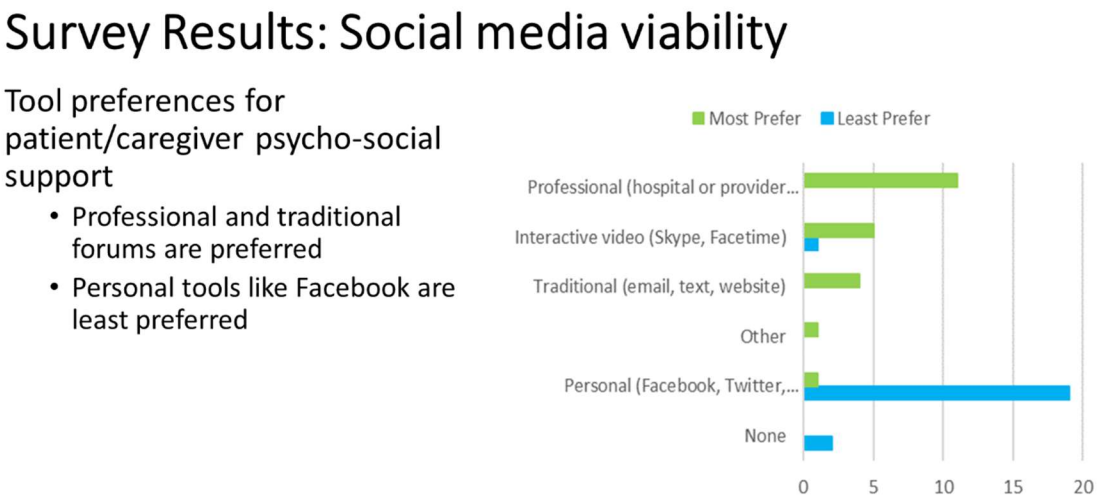


Figure 18. Survey Results – Social Media Reasons for Tool Selection

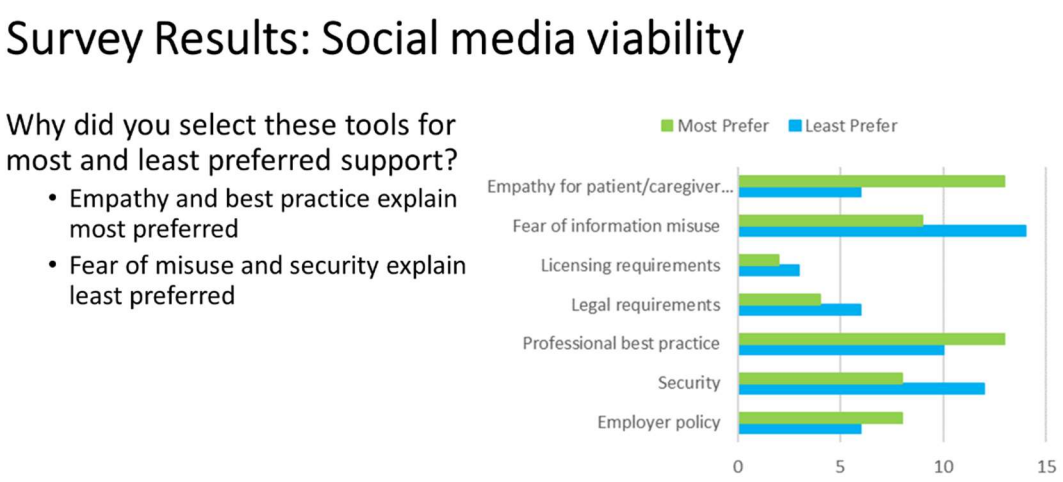
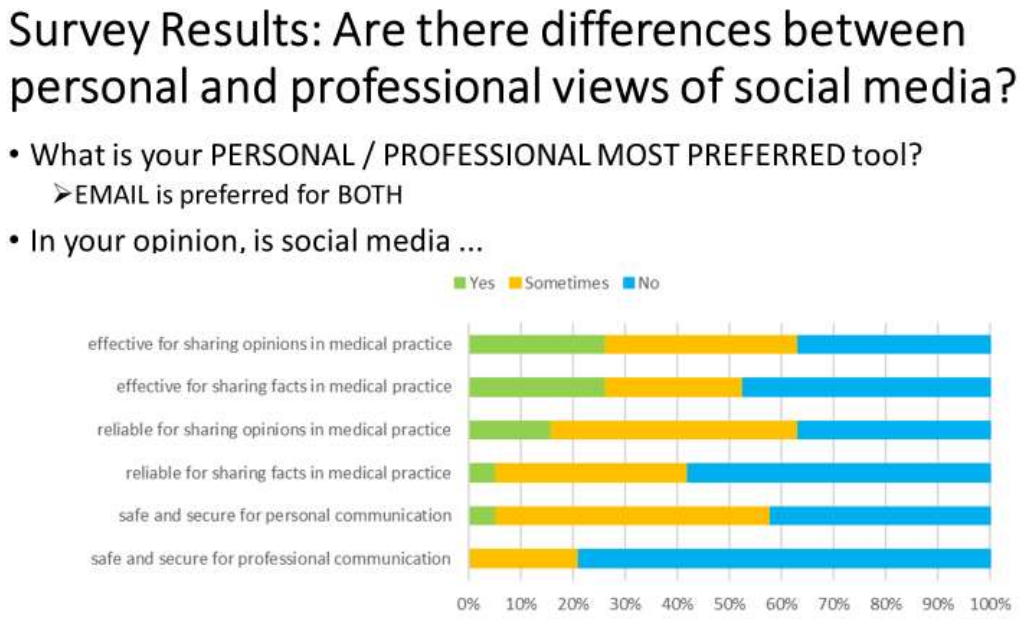


Figure 19. Survey Results – Differences between personal and professional Social Media



5.4 Secondary Data Assessment

Secondary data collection for this study also included review of 70 National Comprehensive Cancer Centers websites (NIH Sites) in the United States. These are the

entire set of organizations which receive significant government funding for cancer research and adhere to strict guidelines for quality of care as well as funded research. This list was combined with a list of selected support resources from the Purple Pages by Circle of Care, a Connecticut not-for-profit organization with a 15-year history of publishing an updated resource guide for families of pediatric cancer patients (Circle of Care). During categorization of sites, if a verified additional not-for-profit organization was identified, it was added to the dataset. The organization would be considered verified only if referred by an NIH site and an active website was available to confirm the not-for-profit was operational. The total number of unique organizations investigated was 110.

For each organization website, data was compiled to achieve an assessment of social media capabilities. As some organizations provide multiple social media services, these were listed as separate data items for a total of 187 sites (Appendix F). Out of these, 7 were eliminated since their focus were solely on research, not patient care, resulting in a dataset of 180 capabilities. The database provided consistent criteria for scoring of each capability for each organization site and was used to evaluate the research questions.

The capabilities of the NIH sites were compared to the capabilities of the not-for-profit sites. The nature of social media capabilities were assessed to provide a view of expectations for users of the sites and the degree of enabling interaction based on the definition of social media for this study. Details of social media services each site offered were further documented based on category, service classification, sector, audience type, and content.

5.4.1 Creating a Database and Defining Variables

In the website assessment, it was important to ensure data coding of the services provided by healthcare and not-for-profit organizations was recorded. Each website/page was given a unique identifier, and its name and URL were recorded. Binary classification was entered for characteristics including whether it was NIH supported, a non-medical support service, restricted only to affiliated patients/families, and whether it served as portal/gateway. Sector, Category, Service Classification, and Formats were coded and binary content characteristics were recorded for interactive, moderated/facilitated, and requires login (Table 10). Lastly, audience, Social Media, and other content characteristics were coded (Table 11).

Table 10. Coding sector, category, and service

Sector	Category	Sub-category	Service Classification	Format
Not-for-profit	Information - physical copy	Story - single broadcast communication	Financial	Other tangible deliverable
University	Information - electronic link	Blog - series of stories	Interpersonal	Website
Commercial	Information - electronic document	Forum – interactive	Organizational	Application
Other/ Unspecified	Discussion-personal	Not recorded	Patient Perspective	Discussion
	Discussion-forum		Research	
			Technical	

Table 11. Coding audience and social media perspectives

Audience Type	Audience Sub-type	Social Media	Perspective	Content Provider
Patient	Child	Facebook	Person	Professional
Patient Circle	Teen	Twitter	Organization	Personal
Professional	Sibling	Instagram		
	Parent/Caregiver	Other public service		
	Friend/Community	Other private service		
	Medical provider			
	Non-medical provider			
	Other or unspecified			

5.4.2 Coding Website Resources

The full dataset obtained from this coding is provided in Appendix F and a summary of the results is illustrated in Figure 20. After 7 websites were excluded due to their research-only services, the remaining were balanced among university and not-for-profit organizations where the university sites represented NIH Cancer Care Centers which were affiliated with research universities and provided clinical patient care. Data showed Patient Perspective as the most frequent services offered. Not surprising, that the secondary service for the Comprehensive Cancer Centers was Technical which represented medical services, and the secondary service for not-for-profits was Interpersonal, generally representing family support groups and other services. Figure 21 illustrates additional services available including social media sites external to patient care facilities and a sample of Facebook pages / groups for support. By no means are these sites or groups exhaustive. They were identified through the assessed websites and are an example of public data availability that can be investigated in future studies.

Figure 20. Website Review Results

Website Review Results – Submitted for Publication

Social based support service sectors investigated for pediatric oncology

Sector	Number of investigated sites
Government (.gov)	2
For-profit (.com)	14
University (.edu)	86
Not-for-profit (.org)	85
TOTAL	187

7 sites were research only / did not provide support services

Social media capabilities by factor

Factor	Comprehensive Cancer Centers	Not-for-Profit Services	Other (Government / For-profit)	Total Number Service Providers
Financial	0	3		3
Technical	11	4		15
Organizational	7	3		10
Patient Perspective	62	50	3	115
Interpersonal	2	22	13	37
TOTAL	82	82	16	180

Figure 21. Additional Website Review Results

Additional Website Review Results

Social media sites external to patient care facilities

Application/Site	Purpose
Caringbridge.org	To inform patient families and communities
Lotsahelpinghands.com	To organize help for patient families
Belong.Life	To create social community
Inspire.com	To learn from others with similar situations
Facebook.com	To share with members who have common interest
Connections (mskcc.net)	To connect resources at one provider institution

Sample of Facebook Pages/Groups for Support

Boston Children's Hospital	National Pediatric Cancer Foundation
Camp Rising Sun	Pediatric Cancer Awareness 24/7
Circle of Care Parents Group	Pediatric Cancer Foundation
Dana-Farber Cancer Institute	Pediatric Cancer Networking
Karmanos Cancer Institute	Stand Up to Cancer
The Leukemia & Lymphoma Society	Whip Pediatric Cancer

5.4.3 Visualizing Website Results

Figure 22 and Figure 23 provide alternative visualizations of this data. The larger the squares, the more organizations provide these services. Lack of pure government and for-profit organizations as well as the coordination of care through a balance of not-for-profit and university services is notable. On visual inspection of the figures, there is less content that is interactive to support the patient and the patient's caregiving circle as compared to non-interactive content. Fortunately, available services are child focused. Analyzing these two representations sets the stage for the final phase of this dissertation research by guiding the selection of a subset of organizations for further review.

Figure 22. Social Media Support Services by Category

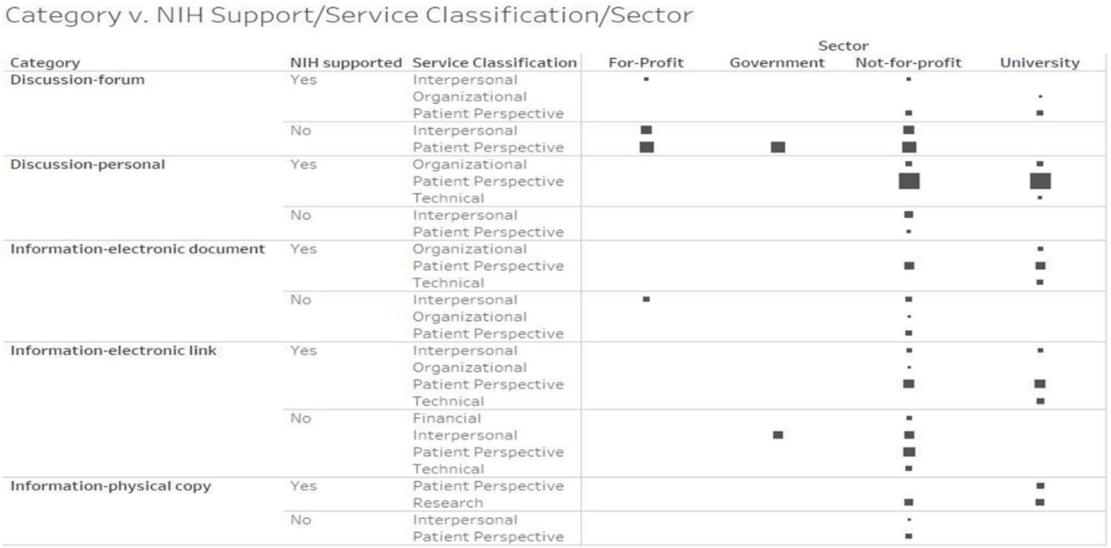
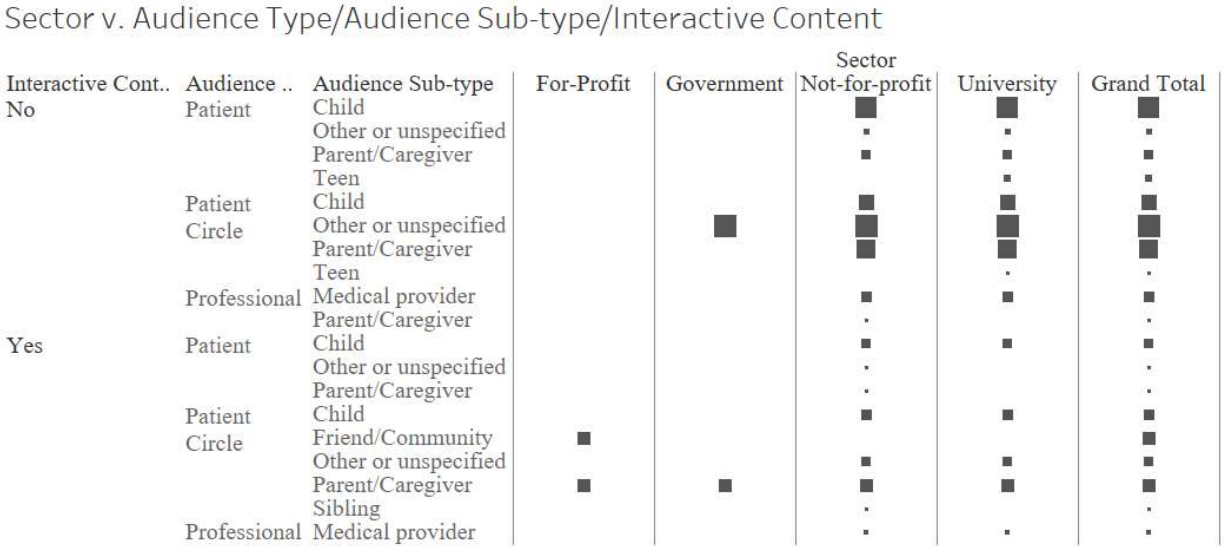


Figure 23: Analysis of Social Media Support Services Content by Sector



5.5 Discussion of Website Results

There are different groups for the purpose of technology adoption among the pediatric oncology stakeholder community. These were identified as professional (medical providers, care-facilitating and not-for-profit organizations), patient circle (parents, extended family, caregivers, friends, and community), and patient (e.g. child vs teen). There were differences in perceptions of social media feasibility and desirability between groups and their subgroups. Medical professionals are concerned about personal and organizational liability, professional licensing, and upholding standards of care. Professional care-facilitating and not-for-profit organizations are concerned about accurate, trusted information sharing. The patient circle is concerned about advice,

support, and hope while maintaining privacy. The patient like other children and young adults, requires mentoring to use technology responsibly.

Services were analyzed by the percentages of social media format, sector, service classification and type obtained from the data (Figure 17 and Figure 18). Websites are most widely used format (37.43%) for access to support services more than discussion with medical providers (24.06%). Other technology applications (22.46%) has promise of future technology enabled services. There is a remarkable balance between university and not-for-profit sector services to demonstrate critical partnerships in psycho-social support for patients and the patient circle. For-profit and government have a less prominent role currently. Social media support service is substantially focused on patient perspective (61.5%). Interpersonal services (19.79%) such as support forums and groups enabled by social media technology are the next most prominent, with each of the other classifications by Spatar, Kok, Basoglu, and Daim (2019) under 10% of the total number of services. Social media types are emerging with Twitter and Instagram each under 2% and Facebook having notable influence (6.95%). Consistent with findings relating to medical provider trust, private services (58.82%) outnumber public services (32.62%). The unbranded services were classified by the social media definition explained.

Several sectors were investigated which provide social based support services to pediatric cancer patients and caregivers. Findings indicated capabilities of the NIH Comprehensive Cancer Care Center websites as portals to social media tools. Of the NIH sites with research sites excluded, there were 86 support services documented representing 100% of the total number of institutions. The not-for-profit organizations

studied while not exhaustive offered 85 services at least 22 of them were not simple resource guides or websites providing links.

The variety of social media capabilities varied. Government relies on NIH funded centers to provide service. For-profit services are subcontractors of NIH centers or not-for-profits. Patient perspective is substantially represented with 115 service providers. The most frequently offered tools were links to not-for-profit organization resources on a website page, discussion groups (at a clinic or less frequently offered online), and story sharing (vignette with/without photo or a posted video). While mobile applications and caregiving services were not widely available 6 sites provided these services.

There was a range of usage for the services including patients, parents, caregivers, family, friends, community, medical providers, and other interested parties. The commercial sites extended this variety to research, pharmaceutical and insurance companies as well as companies offering support products or services to those with the indicated medical condition. In this study there were 12 Facebook groups providing social support that have vetted reliable organizations monitoring content (Appendix F). Data was not studied comprehensively for additional Facebook groups associated with pediatric oncology camps in the US. Although there are more than 100 camps which provide services to the patient circle, most have a primary mission as summer experiences for children and teenagers and are not social media focused for psycho-social support. Findings with data intentionally limited to NIH supported institutions and referrals from the Circle of Care Purple Pages, indicate there is 1) introduction of social media technology capabilities for psychosocial support and 2) potential acceptance by medical and non-medical service providers as well as patients and their caregivers

5.6 Case Study Selection and Results

5.6.1 Process for Case Selection

The method to select cases began with 187 websites and continued by excluding 7 as they provided research only and no support services. Of these 180 websites after for-profit and government were excluded, 171 candidates remained. These were filtered to the 62 URLs where non-medical support was restricted to affiliated patients and families. Then duplicates offering multiple services were removed to achieve 34 organizations (18 medical, 16 non-medical). The final filter criteria enabled 13 cases to be selected (Table 12 below and data in Appendix G). The filters were different for the 7 medical which were included for focus on person and patient perspective and the 6 non-medical. The non-medical organizations included were not-for-profits where cancer was the primary mission and service extended beyond the local geography. Examples of excluded organizations are those which had art, music, religion, or camping as their primary mission and technology-enabled delivery was not aligned with the primary focus of the organization mission.

Table 12. Case Study Organizations

CASE ID	Organization	Date	Time
1	American Childhood Cancer Organization (American Childhood Cancer Organization, 2020)	5-Apr-20	14:50
2	Robert H. Lurie Comprehensive Cancer Center (Robert H. Lurie Comprehensive Cancer Center, 2020)	5-Apr-20	15:15
3	Sidney Kimmel Comprehensive Cancer Center (Sidney Kimmel Comprehensive Cancer, 2020)	5-Apr-20	15:35
4	ASK Childhood Cancer Foundation (ASK Childhood Cancer Foundation, 2020)	5-Apr-20	15:43
5	Sidney Kimmel Cancer Center at Thomas Jefferson University (Sidney Kimmel Cancer Center at Thomas Jefferson University, 2020)	5-Apr-20	15:59
6	Memorial Sloan-Kettering Cancer Center (Memorial Sloan-Kettering Cancer Center, 2020a)	5-Apr-20	16:09
7	Roswell Park Comprehensive Cancer Center (Roswell Park Comprehensive Cancer, 2020)	5-Apr-20	16:15
8	City of Hope Comprehensive Cancer Center (City of Hope Comprehensive Cancer Center, 2020)	5-Apr-20	16:25
9	UC Davis Comprehensive Cancer Center (UC Davis Comprehensive Cancer Center, 2020)	5-Apr-20	16:35
10	Alex's Lemonade Stand Foundation (Alex's Lemonade Stand Foundation, 2020)	5-Apr-20	16:43
11	Children’s Brain Tumor Foundation (Children’s Brain Tumor Foundation, 2020)	5-Apr-20	16:50
12	CancerCare (CancerCare, 2020)	5-Apr-20	17:00
13	The National Children's Cancer Society (The National Children's Cancer Society, 2020b)	5-Apr-20	17:10

Table 13. Private and Proprietary Organization Services

CASE ID	Alt URL	Comments
1	www.inspire.com/groups/american-childhood-cancer-organization	24 Hour Online Peer Support via Inspire
3	www.weibo.com/hopkinsmedicine	Chinese social networking site (microblogging)
6	https://mskcc.net/	Proprietary on-line community
7	https://community.roswellpark.org/	Proprietary on-line community
13	https://leatt.thenccs.org/	Proprietary late effects tool

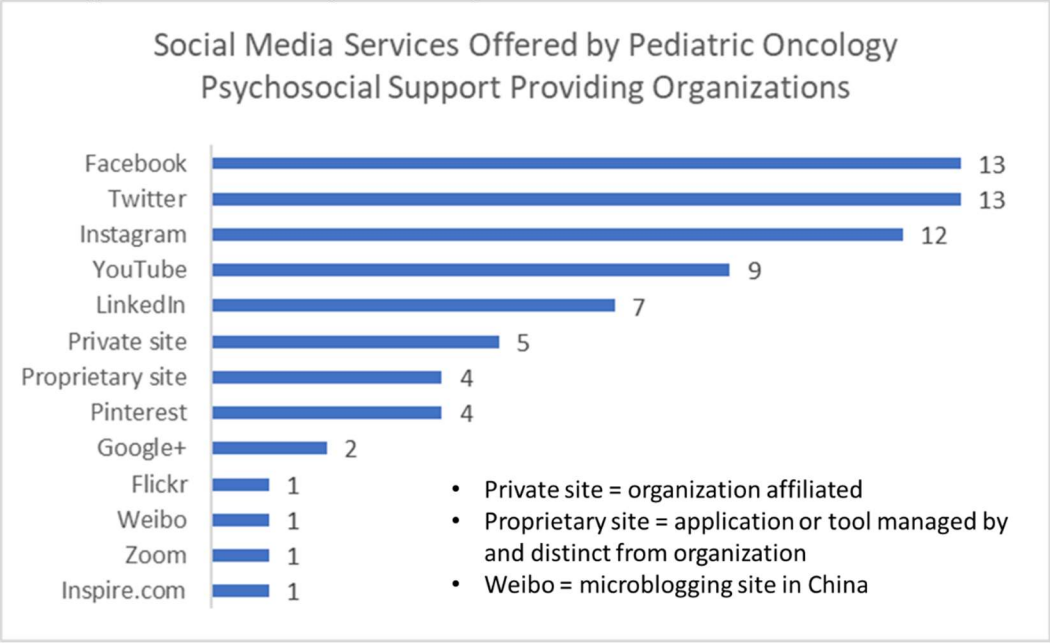
5.6.2 Organization Capability Results from Cases

Coding of 13 sites systematically selected provided some clear results. Sites coded for social media availability demonstrated differences among organization use. Indeed, many organizations delivering pediatric oncology psychosocial support services use social media to communicate with their stakeholders. These services are illustrated in Figure 19. Facebook, Twitter, and Instagram are the most frequently referenced services in the cases studied. YouTube, LinkedIn, and Pinterest are secondary services utilized. Google+, Flickr, and Zoom are referenced selectively.

Cancer centers and not-for-profit organizations use private and/or proprietary sites for patients and families to offer a range of support services and moderated content. Proprietary platforms address patients / caregiver concerns such as support for siblings and cancer long-term effects. They allow the organization to manage applications while controlling user access for stored or shared data. Examples include Memorial Sloan-Kettering (mskcc.net), Roswell Park (community.roswellpark.org), Alex's Lemonade

Stand Foundation (Supersibs!), and The National Children's Cancer Society (leatt.thenccs.org). American Childhood Cancer Organization outsources to Inspire.com, a public platform for health communities not limited to pediatrics. Inspire.com provides support services and security features not available on general social media. Links to all of these sites are provided in Appendix G documenting the template used for collection of the case study data.

Figure 24. Case Study Results by Service



Social media use for pediatric oncology patient and caregiver psychosocial support is available and utilized. A variety of services are provided with websites as the access portal. Stakeholders served include child/patients, caregivers, medical and psychosocial providers, and the community that supports them. Service platforms are internet based with some available to the public; however, richer content and targeted community by disease or provider organization is accessed via proprietary sites. Organization sites

provide 24x7 support availability and are moderated to protect patient/caregiver security and privacy with articulated terms of use.

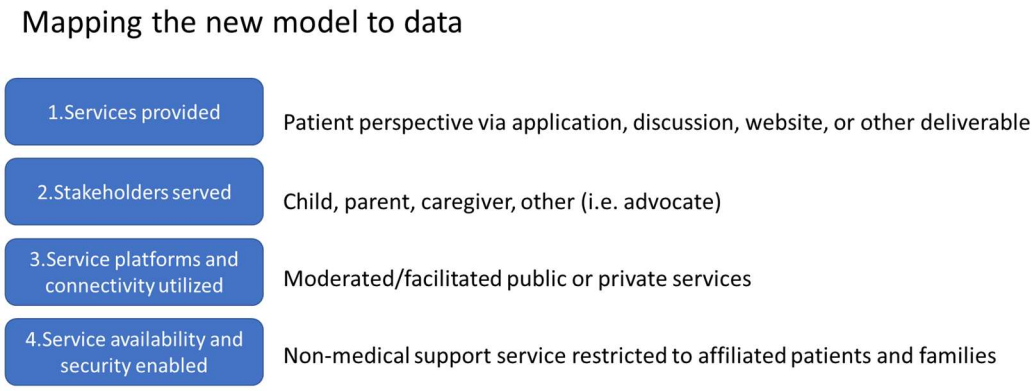
6 ANALYSIS AND DISCUSSION

6.1 Analysis of mapping data to a conceptual model

Expert survey responses provided an initial data source for conceptual development of an integrated platform framework to contribute to solving this problem. Medical experience and psychosocial support, technology in practice and choice of software/apps, and social media, employer policy / legal concerns are the pillars of this platform. Recognizing that these pillars each have different maturity levels for their content, a physical platform would need to address databases and structured data, web-based unstructured content, as well as the emerging availability of mobile and sensory content so that it can organically grow to meet the needs of medical providers, patients, and caregivers. The pediatric oncology community is compelling and provides a data source for research based on established contacts, while the technology management community provides a gateway to the infrastructure enabling the core purpose of this work: If each patient has a unique situation, caregivers can be empowered to leverage technology and relationships to affect health outcomes.

The 13 cases data captured are listed in Appendix G and screenshots are documented in Appendix I. Coding of the cases to the new model was achieved by mapping the criteria from the website analysis to the independent variables in the model (Figure 25).

Figure 25. Model Mapping



The website analysis data was used as case selection filter criteria. Cases were selected for the services provided when the organization delivered patient perspective services via an application, discussion, website or other format. In person face to face meetings with medical or behavioral health providers were excluded from these criteria as it would not be classified as social media in the definition of this research. Similarly, an analogous telemedicine visit would not quality as it could be considered a simple shift from in person to electronic communication. The differentiator is the social aspect of the media changing the paradigm of how technology enables psychosocial support. The question to answer from analysis of the organization capabilities was "Does this organization provide services via social media which use technology to enable psycho-social support for pediatric oncology patients and caregivers?"

Similarly, the website analysis data was used as case selection filter criteria for stakeholders served. This information was also recorded in the website collection spreadsheet. If the organization provided an array of services not only to patients, but also to caregivers, siblings, medical teams, the general public, and other stakeholders (e.g. researchers or individuals and organizations interested in fundraising for the benefit of

the primary stakeholders), then the organization was viewed as proactive in using social media to provide technology-enabled support to stakeholders.

The service platforms and connectivity utilized varied widely. Each case was reviewed to consider what services were offered and how the services were managed. All cases were active with the most popular social media sites (Facebook and Twitter). The diversity in selecting which sites to support was considerable for secondary and tertiary public services. Notable exceptions were the use of private and proprietary sites. A private site is a way of outsourcing the capability to a service like buying an apartment in a co-op or a vacation timeshare. The site would be branded for the organization paying for the service and must meet contractual service level obligations for content and connectivity. A proprietary site represents significant investment and maintenance cost for the organization. Resources to develop and maintain it must be allocated. The benefit of having complete control over the site could be an advantage for the organization in providing quality patient care and resources to caregivers if the obstacles of technology adoption can be overcome.

Enabling service availability and security was measured in the website assessment data based on whether the services and platforms used were restricted to patients and families of that hospital. Many of the websites explicitly stated what services were available 24x7. Others required a system administrator to approve access requests. Some required posts to be reviewed before being made publicly available. Others required verification of being a patient of that hospital. Using these criteria in the model provided the benefit of excluding the occasional curious individual to target the technology user

with real need and who does not choose a medical or behavioral therapy approach to obtain support.

6.2 Discussion

Data supports assertion by Redekop, Bakker, and Aarts (2018) that healthcare problems rely on many factors to solve them and healthcare technology alone is not sufficient. Organizations like the Patient Centered Outcomes Research Institute (Patient-Centered Outcomes Research Institute) have achieved attention and changed the way healthcare is delivered. The economics of healthcare weighs heavily not only on families that are experiencing a child's diagnosis and treatment, but also on that child who becomes an adult with a lifelong history to monitor (Nipp et al., 2017).

6.2.1 Patient and Caregiver Support

Early phases of this research indicated a low social media literacy level and some resistance to change by medical professionals in the hospital or clinic setting (Belitzky et al., 2019). The results were consistent with Kuek and Hakkennes (2019) who studied healthcare staff digital literacy levels. These findings are inconsistent with the demand from patients and caregivers who look to social media and other technology as a convenient and reliable information source regardless of the truth in accurate reporting and risks to privacy and security. Learning from a historical literature review (Woodgate, 1999) demonstrates that the problem will not disappear and is a call to action now that technology is readily available to the public.

6.2.2 Knowledge Management Technology

Patients and caregivers are health information seeking and rely on technology tools like mobile phones as aids (Deng, Liu, & Hinz, 2015). With organizations developing capabilities to serve their stakeholders, there are more current studies to assess the use of electronic devices to obtain health information (Greenberg-Worisek et al., 2019). Knowledge management technology has been recently studied in the context of chronic illness and long-term care (Lo & Ng, 2019) The data in this study begins to illustrate opportunity for additional work specifically to address the knowledge management requirements of pediatric oncology patients and caregivers whose data is likely to be stored in multiple systems and change ownership and access controls over the information lifecycle. Additionally, the unstructured data which social media may provide to broader public health concerns discussed by the patients and caregivers on technology platforms over time is unknown.

6.2.3 Healthcare Technology and Social Media

Far from ubiquitous a decade ago, there was published work on cancer survivorship and social media (Chou, Hunt, Folkers, & Augustson, 2011; Chou, Hunt, Beckjord, Moser, & Hesse, 2009). At that time one would not have envisioned that social media would be a lifeline for pandemic daily living. More so, the impact is exponential for cancer survivors who today rely on social media for interpersonal support and human interaction (Chou et al., 2009). The 2020 summer camp experience has been converted to social media via Zoom and other tools (Camp Rising Sun, 2019). For many caregivers who typically use the short time of summer residential camps as respite, they will find solace in connecting with others on social media (Gabriel et al., 2017). The data provide

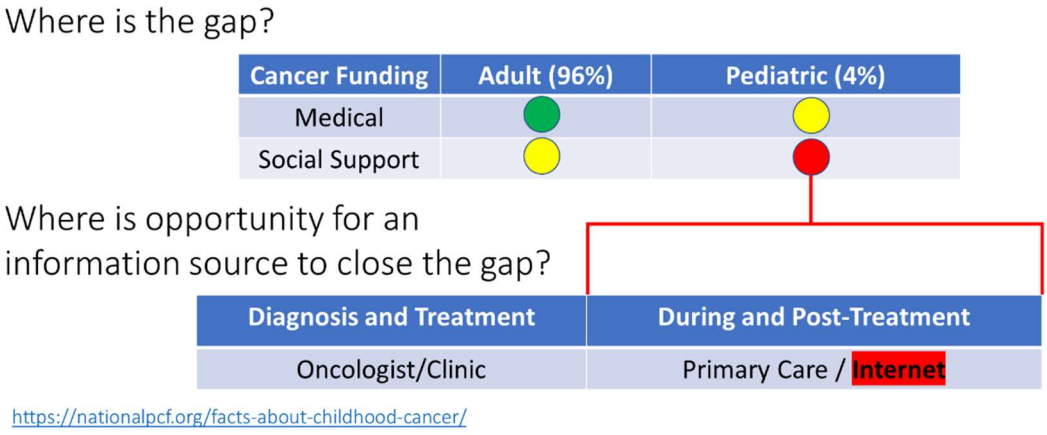
evidence that both healthcare organizations and not-for-profit organizations use social media in a fragmented way and that there is opportunity for partnering to provide a wholistic user experience for patient and caregiver.

7 CONTRIBUTION, IMPLICATIONS, AND LIMITATIONS

7.1 Contribution

There are several contributions of the proposed research. Initially, there is value in defining the gap (Figure 26). Use of the case study approach builds on the precedent of technology delivered stories. There have been public examples of the success this methodology provides which may not be appreciated in academia. For example, at Ellis Island in New York, an immigrant database provides information for people who seek knowledge of their ancestors who settled in the United States. At the Holocaust Memorial Museum in Washington, DC there are exhibits with recorded survivor reflections and testimonies which represent the truth of human experience available for future generations to learn. Similarly, at the 911 Memorial on the site of the World Trade Center in New York, the names, chronology, education of those who perished provide powerful stories which bring remembrance and healing to those who visit.

Figure 26. Technology-Enabled Psychosocial Support Source



This research can provide value by sharing information across organizations. Providers may currently have limited knowledge of resources available to them outside

their own geographic service area. Examples of these organizations include United States National Institute of Health cancer centers (National Institute of Health), not-for-profit organizations, oncology camps, and private research institutions. Beneficiaries of these services reach beyond the patient across life stages of child, teen, young adult, adult survivor to parents, family, other caregivers, and friends.

The July 2019 inaugural symposium of the Childhood Cancer Data Initiative (CCDI) (Childhood Cancer Data Initiative) took an initial step to recognize these contributions and a working group report was approved in June 2020. CCDI represents a US federal investment of $50 million which aims to "allow the National Cancer Institute (NCI) (National Institute of Health) to enhance data sharing, collection, analysis, and access for ongoing and planned childhood and AYA [adolescent and young adult] cancer and survivorship research". CCDI participants represent a broad range of stakeholders. Initial CCDI effort is to share basic science / biological specimen data and trace patients over time from diagnosis through treatment and beyond.

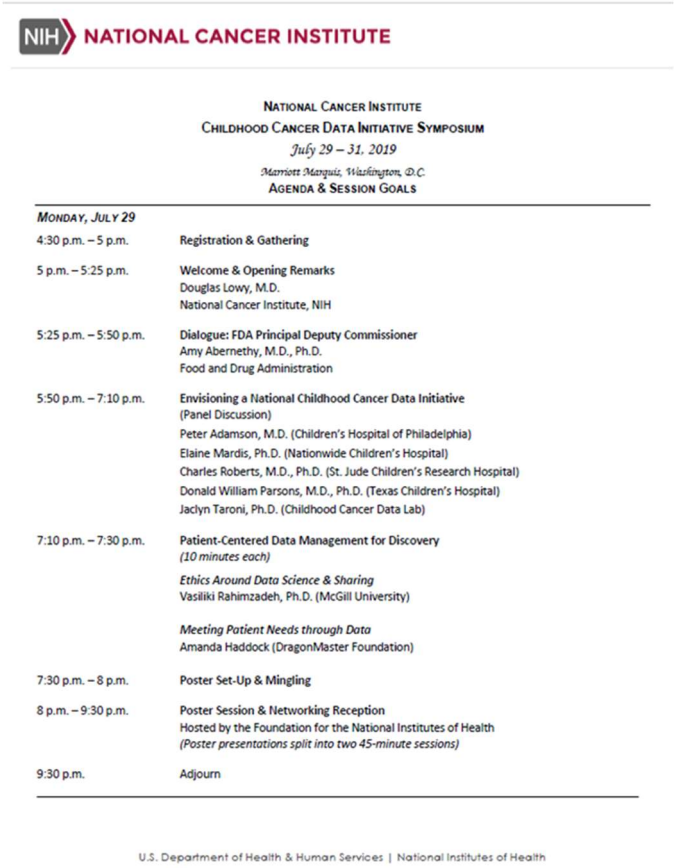
In the long term, this dissertation provides a platform to realize a research vision to supplement the medical data with psychosocial data. It demonstrates how a federated model for data sharing via stories and social media might be leveraged, and it enable researchers to use this data to improve support for survivors. The impact of this research may support self-advocacy for pediatric patients when they become adults and provide proactive support to families who need to address mental health issues. Data identifies where caregivers may find on-demand support during and post-treatment and help them

extend their ability to access resources outside their own communities and health care provider network (National Coalition for Cancer Survivorship).

This research creates a focus on improving quality of life for childhood cancer survivors, families, and caregivers who suffer with health conditions. It brings attention to the void of supplementing medical provider support with secure, reliable psychosocial support delivered via technology. The undocumented time a survivor spends seeking psychosocial support compared to medical support may be substantial. Anecdotal evidence estimating this comparison would suggest, other than sleep and school, a pediatric survivor who has completed treatment spends 1-3 hours/week on medical follow-up appointments (excluding travel time) compared to 1-3 hours/day for individual therapy, group counseling, tutoring, and family discussion related to the impacts of diagnosis, treatment, and longer term impacts. Fifteen years ago, researchers identified funding, methodology, and partnering would be factors to assist with psycho-oncology investigation (Patenaude & Kupst, 2005).

Survivorship in this study begins at diagnosis and continues through the patient's lifespan. For children, caregiver(s) makes survivorship decisions on behalf of the patient with medical team support; hence caregivers are important stakeholders to include in the research along with patients and medical providers. In sum, the frame of the research hypothesis is that technology-enabled psychosocial support influences stakeholders who seek not only survivorship, but also quality of life during the onco-care lifecycle.

Figure 27. CCDI Symposium Agenda (Excerpt) (Childhood Cancer Data Initiative)



NIH NATIONAL CANCER INSTITUTE

NATIONAL CANCER INSTITUTE
CHILDHOOD CANCER DATA INITIATIVE SYMPOSIUM
July 29 – 31, 2019
Marriott Marquis, Washington, D.C.
AGENDA & SESSION GOALS

MONDAY, JULY 29	
4:30 p.m. – 5 p.m.	**Registration & Gathering**
5 p.m. – 5:25 p.m.	**Welcome & Opening Remarks** Douglas Lowy, M.D. National Cancer Institute, NIH
5:25 p.m. – 5:50 p.m.	**Dialogue: FDA Principal Deputy Commissioner** Amy Abernethy, M.D., Ph.D. Food and Drug Administration
5:50 p.m. – 7:10 p.m.	**Envisioning a National Childhood Cancer Data Initiative** (Panel Discussion) Peter Adamson, M.D. (Children's Hospital of Philadelphia) Elaine Mardis, Ph.D. (Nationwide Children's Hospital) Charles Roberts, M.D., Ph.D. (St. Jude Children's Research Hospital) Donald William Parsons, M.D., Ph.D. (Texas Children's Hospital) Jaclyn Taroni, Ph.D. (Childhood Cancer Data Lab)
7:10 p.m. – 7:30 p.m.	**Patient-Centered Data Management for Discovery** *(10 minutes each)* *Ethics Around Data Science & Sharing* Vasiliki Rahimzadeh, Ph.D. (McGill University) *Meeting Patient Needs through Data* Amanda Haddock (DragonMaster Foundation)
7:30 p.m. – 8 p.m.	**Poster Set-Up & Mingling**
8 p.m. – 9:30 p.m.	**Poster Session & Networking Reception** Hosted by the Foundation for the National Institutes of Health *(Poster presentations split into two 45-minute sessions)*
9:30 p.m.	Adjourn

U.S. Department of Health & Human Services | National Institutes of Health

7.2 Implications

For over thirty years researchers have anticipated the ubiquitous use of artificial intelligence for decision making. Replacement of humans not only for routine tasks, but also for tasks requiring judgement has been an unrealized aspiration. There have been leaps in capabilities of technology and its applications. Yet, there have been only small steps by people accepting that change is inevitable due to technology-enabled healthcare delivery. Prior to effective institutional change where life decisions are base to their existence, healthcare leaders demand concrete, research-based evidence to embrace new ways of working. Visualizing medical practice, patient care, and caregiving as interconnected systems (Muralidharan et al., 2011) may enable a viewpoint to rethink

provision for quality care. Including caregivers in structuring patients' information network can improve quality of life. Knowledge management and social media provide perspectives on how to do so (Ford & Mason, 2013a)(Ford and Mason, 2013 and Razmarita et al., 2014).

Knowledge management systems have matured; however, the social constructs and standards of communication and collaboration for all stakeholders in the patient universe have been slower to adapt. The use of Facebook and the controversy in the media regarding its data and privacy practices is a popular example of the best and the worst that changes in technology bring to individuals and organizations. One would expect that public adoption of technology to manage knowledge would lag the available capabilities. A system must be developed and implemented for someone to use it. It is the agile and iterative process of system development that is powerful as well as dangerous. Developers require users to test application features and feedback on product viability. Healthcare knowledge management technology consumers must be educated to understand that adoption of these new applications means that their privacy and information security may be at risk. Nonetheless, with this learning, the population of patients and caregivers using knowledge management systems will become savvy and demand quality solutions to real world problems.

There are many caregiver challenges. Years of managing delivery of information for providers across multiple health systems is a burden. Obtaining consistency in distribution lists so that one's entire medical and support team is included in correspondence requires expert administrative skills. Attention to security is important

for a patient using social media to include or exclude primary caregiver, family, friends, and others in one's personal network. Architecting an integrated platform which puts the patient first and is easy for everyone in the system to use is still an unrealized objective. Such a platform must provide structured data as in an electronic health record as well as unstructured data as in social media used as a knowledge management system.

Implications for research to achieve this objective involve data and organization challenges. There are fast moving technology updates yet limited secondary data. Data that may be available is regulated so not shared. Privacy and security are non-negotiable for pediatric patients which makes primary data a greater obstacle to obtain. Healthcare systems are slow moving organizations resistant to change. While federated models with formally agreed sharing services may achieve benefits, the legal work required requires resources that have not been allocated.

This research has been a solo effort personally funded by the author. However, institutional support from one or more university, hospital, or not-for-profit organizations would be critical to a future research program. Researcher bias was controlled by two mechanisms. First, objective survey and website data were assessed while informal conversations were only used for understanding context. Second, the researcher did not have any personal experience or professional relationships with the l3 organizations identified for the case study. This independence is important for credibility of results. There are many opportunities to conduct research on technology and psychosocial support and limited support to do so because the personal nature of the subject. Success may be more likely with institutional cooperation fueled by demand from caregivers

when caregivers become advocates for communal resources. The data supports that medical organizations must make medical care a priority. The data also supports that the role of the not-for-profit sector is complimentary and will have longevity in partnering with healthcare organizations. Investigator bias (i.e. a researcher having personal experience with pediatric oncology), if controlled with respect to data collection and analysis, can bring substantial value to the research conclusions and any actions taken for public benefit as an outcome.

7.3 Limitations

There are limitations from this research that would be immediately recognized by a quantitative researcher using scientific method. The integrity and validity of the data and the lack of statistical analysis are obvious concerns. Researcher bias and the volatility of organization use of social media tools would be others. However, there are more significant benefits to not having only an extensive literature review, but also a time capsule of documented services which can be compared with services offered in the future. Acknowledging the speed of change and stakeholder adoption of social media, there is credibility in the use of National Institute of Health information sources through sponsored organizations and not-for-profit services who also operate nationally in the United States. There is credibility in .

8 FUTURE RESEARCH

One informal conversation suggested the role of data advocate to bridge the communication gap between researchers, the medical community, caregivers, and patients. The next steps of a research program would start with a comprehensive review of the accepted June 15, 2020 recommendations of the Childhood Cancer Data Initiative working group. That effort would be followed by creating a partnership network, drafting a project scope, forming an advisory committee, affiliating with a sponsoring organization, and submitting grant applications. The Momcologist Foundation (Momcologist Foundation) may provide a substantial pre-built network to accelerate this process. This organization has experienced considerable growth in 2019-2020 and defines its membership with clear branding to establish a strength of identity.

Such branding could be helpful to support a tactical proposal. One proposal option to define a logical architecture design would be to compare the American Childhood Cancer Organization use of Inspire.com with the capabilities available through Memorial Sloan-Kettering's and Roswell Park's proprietary systems. Such a technical requirements study may identify a set of functional, technical, and security requirements to benefit a broader stakeholder base than currently use these systems individually. Collectively, this study might also provide insight on scaling service beyond a single institution and extend public, private, and not-for-profit partnerships.

9 CONCLUSIONS

Technology-enabled psychosocial support for pediatric oncology patients and caregivers via social media has potential to improve quality of life. The research questions posed have answers. Who are the stakeholders influencing technology use and what are their adoption criteria? Stakeholders not only include patients and caregivers, but also include healthcare providers. They require privacy, security, and reliable content/forums to adopt technology. What organization enablers can be motivated to achieve use case objectives? Organizations enabling support rely on proprietary and public services. Change management capability is important to drive adoption. Resources must be allocated with technology, content curation, and interpersonal facilitation skills. Are there best practice examples available and what can be learned from them? Case studies identified several best practice organizations. The learning from these cases is to use multiple platforms and tools, share resources, protect personal information, scale services iteratively, and allocate time and funds to keep technology-enabled support services updated.

For social media to be accepted as a vehicle for technology-enabled psychosocial support in pediatric oncology, healthcare organization changes are required. These changes can include improvements in stakeholder trust, planning, information quality and reliability, and risk management. This early stage of maturity provides opportunity for research. Results from limited data translated to initial lessons learned representing tenets of a successful platform where social media is linked to data provided by organization information systems and knowledge management repositories both internal and external to the organization.

These lessons do not specify exactly what to do and how to work. The lessons do provide insights in the same way a good doctor would provide advice to a patient caregiver when the patient could not self-advocate. Setting professional-personal boundaries is a starting point. If the boundaries are adjustable it may increase the platform's longevity. Adhere to the non-negotiable security and privacy standards as well as laws, professional codes of conduct, and ethical norms, while respecting patient/caregiver wishes. Publish policies and monitor adherence to quality standards. Use continuous improvement processes to facilitate communication and evolve capabilities. As caregiver decision making, like those for any leadership role, can be lonely, caregivers can be instructed to make disciplined decisions relying on fact-based evidence as well as social concerns. This research suggests there is opportunity for social media to support decision making on several dimensions without compromising risk factors via an umbrella platform using many data sources, communicating reliability of information, and providing a secure, convenient, user-centric interface.

There are opportunities to extend what is available today for research in pediatric oncology caregiving. The patient, and by proxy, caregiver experience is a journey which begins before diagnosis and continues past the end of a patient's life. Research has had focus on identifying and treating illness, curing disease, and managing health care systems (doctors, hospitals, laboratories, and social services). The patient-centered outcome focus is relatively new with organizations such as PCORI (www.pcori.org) dedicated to this mission established in the past decade. In parallel, the plethora of information technology and social media capabilities has exploded in the same timeframe. The health care industry like other industries is in a race to enable the benefits

available. Unlike other industries, when human life is on the line, financial risks are significant, and public support of a litigious society is rampant, the healthcare industry moves ahead with cautious optimism. There is a monumental change management task to accomplish.

Opportunities for future research are abundant. Because the pediatric oncology community in the United States is supportive and collaborative, healthcare researchers, medical practitioners, patients, and families have a unique breeding ground to further a platform for best practices and improving systemic outcomes for all stakeholders. Some of the problems this work may address include the virtualization of healthcare experience using technology, communication and teamwork between providers and patients/caregivers, seamless deployment of technology tools for timely information sharing, reducing patient/caregiver anxiety and stress while promoting advocacy skills. Historically, efforts may have been considered a bonus, but in the future, knowledge management via both portals and social media could become baseline care expectations

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APPENDICES

Appendix A: IRB Exemption Determination

EXEMPTION DETERMINATION

August 28, 2018

Ellen Belitzky
College of Engineering, Business and Education
University of Bridgeport

Dear Ms. Belitzky:
On *August 28, 2018* a designated IRB representative determined that your proposed study meets the criteria for exemption:

Type of Review:	*Exemption Determination*
Project Title:	Social Media as a Knowledge Management Tool for Pediatric Oncology Caregivers
Investigator:	Ellen Belitzky
Exemption:	45 CFR 46.101(b)(2)
Exemption Description:	Research involving the use of educational tests, survey procedures, interview procedures or observation of public behavior.

Sincerely,
Julie F. Demers
IRB Administrator

CC: Dr. Elif Kongar
Dr. Ruba Deeb

126 Park Avenue • Bridgeport, CT 06604 • Tel: 203.576.4973 • E-mail: irb@bridgeport.edu

Appendix B: IRB Informed Consent

Pediatric Oncology and Social Media

INFORMED CONSENT: Completion of this anonymous survey is part of a University of Bridgeport research study, your participation is voluntary, and you may withdraw at any time. The purpose of this survey is to collect expert opinions about current and potential use of social media in pediatric oncology practice. You have been asked to complete this form based on your expertise. Gathered information from experts could inform on the use of social media for personal and professional activities. The survey should take 10-15 minutes at most to complete.

The Principal Investigator is Ellen Belitzky, a Ph.D. Candidate in Technology Management at the University of Bridgeport (ebelitzk@my.bridgeport.edu). Information entered in the survey will be solely used for dissertation research and data for academic publications. Questions are designed to maintain anonymity and prevent the personal identification of responders. In the event individual responses deliberately or inadvertently become personally identifiable, the investigator will destroy this information. Gathered information and detailed survey data will not be used for any other purpose than described herein.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the University of Bridgeport's IRB Coordinator at irb@bridgeport.edu or 203-576-4974.

Appendix C: Survey- Pediatric Oncology and Social Media

* Required

Professional Experience

There are 10 questions in this section. Where there is multiple choice, mark only one, unless specified.

1. **Organization Location**
   - o Connecticut
   - o Other state
   - o Outside USA

2. **If not USA, which country?**

_____

3. **Role** *
   - o Oncologist
   - o Other physician
   - o Psycho-social professional
   - o Other medical role
   - o Non-medical role

4. **Professional sub-specialty, if applicable** (e.g. Primary care physician, Surgeon, Radiologist, Neurologist, Psychologist, Nurse, Social Worker, Child Life Specialist, etc.)

_____
_____

5. **Gender** *
   - o Female
   - o Male
   - o Other
   - o Prefer not to say

6. Years post-graduate education/training (include fellowships) *
- 0
- 1-4
- 5-8
- 9-12
- 12+

7. Years in medical practice *
- 0
- 1-5
- 6-10
- 11--15
- 15+

8. Months professional working outside the USA *
- None
- Less than 6 months
- 6 months up to one year
- 1-2 years
- more than 2 years

9. Primary professional setting *
- hospital
- office
- community center/clinic
- camp
- residential facility
- research
- other

10. Primary population served *
- Urban
- Suburban
- Rural

Service via technology

There are 4 questions in this section. Where there is multiple choice, mark only one, unless specified.

13. I use technology for my initial patient contact. *
Yes No

14. I use technology for my follow-up patient contact. *
Yes No

15. Preferred technology used for patient contact *
- not applicable
- phone
- email
- text message
- patient portal
- video chat (e.g. Skype/Facetime)
- Facebook
- other social media

16. **Please explain the reason for your preference.** *

_____
_____
_____
_____

Social media for psycho-social support

There are 9 questions in this section. Where there is multiple choice, mark only one, unless specified.

17. **What patient psycho-social support do you most often recommend?** *
- o Family/friends
- o Professional counselor
- o Clergy
- o Agency/non-profit
- o Other
- o Do not recommend

18. **What caregiver psycho-social support do you most often recommend?** *
- o Family/friends
- o Professional counselor
- o Clergy
- o Agency/non-profit
- o Other
- o Do not recommend

19. **Do you believe social media can provide psycho-social support?** *
- o Yes
- o No
- o Maybe

20. **Why do you feel this way?**

_____
_____

---

21. **What tools would you MOST PREFER to use for patient/caregiver psycho-social support?** *
- o Traditional (email, text, website)
- o Professional (hospital or provider portal)
- o Personal (Facebook, Twitter, Instagram)
- o Interactive video (Skype, Facetime)
- o Other
- o None

22. **Why did you select these tools for MOST PREFERRED support?** *

Check all that apply.
- o Employer policy
- o Security
- o Professional best practice
- o Legal requirements
- o Licensing requirements
- o Fear of information misuse
- o Empathy for patient/caregiver convenience

23. **What tools would you LEAST PREFER to use for patient/caregiver psycho-social support?** *
- o Traditional (email, text, website)
- o Professional (hospital or provider portal)
- o Personal (Facebook, Twitter, Instagram)
- o Interactive video (Skype, Facetime)
- o Other
- o None

24. **Why did you select these tools for LEAST PREFERRED support?** *
Check all that apply.
- o Employer policy
- o Security
- o Professional best practice
- o Legal requirements
- o Licensing requirements
- o Fear of information misuse
- o Empathy for patient/caregiver convenience

25. **Can you share any specific examples of professional social media use that were either beneficial or detrimental to patients/caregivers?**

_____
_____
_____

Personal vs. Professional Preferences

There are 6 questions in this section. Where there is multiple choice, mark only one, unless specified.

26. **Is there a difference between social media and professional portal online discussions as a resource for patient caregiver information?** *

Yes No

27. **Why do you feel this way?**

_____
_____
_____
_____

28. **What is your PERSONAL MOST PREFERRED tool to communicate?** *
- o Email/text
- o Facebook
- o WhatsApp
- o Twitter
- o Instagram
- o Snapchat
- o Other
- o None

29. **What is your PROFESSIONAL MOST PREFERRED tool to communicate?** *
- o Email/text
- o Facebook
- o WhatsApp

- Twitter
- Instagram
- Snapchat
- Other
- None

30. If your personal and professional tool choices are different, why?

_____
_____

31. In your opinion, is social media ... *

Mark only one per row.

safe and secure for personal communication?	Yes	No	Sometimes
safe and secure for professional communication?	Yes	No	Sometimes
effective for sharing facts in medical practice?	Yes	No	Sometimes
effective for sharing opinions in medical practice?	Yes	No	Sometimes
reliable for sharing facts in medical practice?	Yes	No	Sometimes
reliable for sharing opinions in medical practice?	Yes	No	Sometimes

Social Media Usage

The final two questions in the survey ask for your view on social media appropriateness (efficient, effective, reliable, and secure) for sharing various information in your professional practice?

32. Appropriate Social Media Information Sharing (1-7 scale, 1 being the least) *

Circle only one per row.

Diagnosis	1	2	3	4	5	6	7
Treatment	1	2	3	4	5	6	7
Care plan	1	2	3	4	5	6	7
Medical status	1	2	3	4	5	6	7
Cost of care	1	2	3	4	5	6	7
Insurance	1	2	3	4	5	6	7
Social networking	1	2	3	4	5	6	7
Community interactive meetings	1	2	3	4	5	6	7
Community online discussions	1	2	3	4	5	6	7
Counseling	1	2	3	4	5	6	7
Other psychosocial support	1	2	3	4	5	6	7
Referral services	1	2	3	4	5	6	7
Case studies	1	2	3	4	5	6	7
Research studies	1	2	3	4	5	6	7
Appointment information	1	2	3	4	5	6	7
Medication side effects	1	2	3	4	5	6	7
Hospital admission instructions	1	2	3	4	5	6	7
Hospital discharge instructions	1	2	3	4	5	6	7

33. Do you have any other opinions about use of social media and pediatric oncology not addressed in prior questions?

_____
_____

Appendix D: Survey Data

Q1: Organization Location

ANSWER CHOICES	RESPONSES	
Connecticut	29.41%	10
Other state	58.82%	20
Outside USA	11.76%	4
TOTAL		34

Q3: Role

ANSWER CHOICES	RESPONSES	
Oncologist	14.71%	5
Other physician	0.00%	0
Psycho-social professional	14.71%	5
Other medical role	47.06%	16
Non-medical role	23.53%	8
TOTAL		34

Q5: Gender

ANSWER CHOICES	RESPONSES	
Female	91.18%	31
Male	5.88%	2
Other	2.94%	1
Prefer not to say	0.00%	0
TOTAL		34

Q6: Years post-graduate education/ training (including fellowships)

ANSWER CHOICES	RESPONSES	
0	35.29%	12
1-4	20.59%	7
5-8	11.76%	4
9-12	2.94%	1
12+	29.41%	10
TOTAL		34

Q7: Years in medical practice

ANSWER CHOICES	RESPONSES	
0	23.53%	8
1-5	8.82%	3
6-10	20.59%	7
11--15	11.76%	4
15+	35.29%	12
TOTAL		34

Q8: Months professional working outside the USA

ANSWER CHOICES	RESPONSES	
None	79.41%	27
Less than 6 months	5.88%	2
6 months up to one year	0.00%	0
1-2 years	0.00%	0
more than 2 years	14.71%	5
TOTAL		34

Q9: Primary professional setting

ANSWER CHOICES	RESPONSES	
hospital	70.59%	24
office	11.76%	4
community center/clinic	5.88%	2
camp	5.88%	2
residential facility	0.00%	0
research	2.94%	1
other	2.94%	1
TOTAL		34

Q10: Primary population served

ANSWER CHOICES	RESPONSES	
Urban	52.94%	18
Suburban	35.29%	12
Rural	11.76%	4
TOTAL		34

Q11: I use technology for my initial patient contact

ANSWER CHOICES	RESPONSES	
Yes	41.38%	12
No	58.62%	17
TOTAL		29

Q12: I use technology for my follow-up patient contact

ANSWER CHOICES	RESPONSES	
Yes	55.17%	16
No	44.83%	13
TOTAL		29

Q13: Preferred technology used for patient contact

ANSWER CHOICES	RESPONSES	
not applicable	10.34%	3
phone	51.72%	15
email	31.03%	9
text message	0.00%	0
patient portal	6.90%	2
video chat (e.g. Skype/Facetime)	0.00%	0
Facebook	0.00%	0
other social media	0.00%	0
TOTAL		29

Q15: What patient psycho-social support do you most often recommend?

ANSWER CHOICES	RESPONSES	
Family/friends	27.27%	6
Professional counselor	50.00%	11
Clergy	0.00%	0
Agency/non-profit	9.09%	2
Other	13.64%	3
Do not recommend	0.00%	0
TOTAL		22

Q16: What caregiver psycho-social support do you most often recommend?

ANSWER CHOICES	RESPONSES	
Family/friends	27.27%	6
Professional counselor	54.55%	12
Clergy	0.00%	0
Agency/non-profit	9.09%	2
Other	4.55%	1
Do not recommend	4.55%	1
TOTAL		22

Q17: Do you believe social media can provide psycho-social support?

ANSWER CHOICES	RESPONSES	
Yes	36.36%	8
No	4.55%	1
Maybe	59.09%	13
TOTAL		22

Q19: What tools would you MOST PREFER to use for patient/caregiver psycho-social support?

ANSWER CHOICES	RESPONSES	
Traditional (email, text, website)	18.18%	4
Professional (hospital or provider portal)	50.00%	11
Personal (Facebook, Twitter, Instagram)	4.55%	1
Interactive video (Skype, Facetime)	22.73%	5
Other	4.55%	1
None	0.00%	0
TOTAL		22

Q20: Why did you select these tools for MOST PREFERRED support? (Check all that apply)

ANSWER CHOICES	RESPONSES	
Employer policy	36.36%	8
Security	36.36%	8
Professional best practice	59.09%	13
Legal requirements	18.18%	4
Licensing requirements	9.09%	2
Fear of information misuse	40.91%	9
Empathy for patient/caregiver convenience	59.09%	13
Total Respondents: 22		

Q21: What tools would you LEAST PREFER to use for patient/caregiver psycho-social support?

ANSWER CHOICES	RESPONSES	
Traditional (email, text, website)	0.00%	0
Professional (hospital or provider portal)	0.00%	0
Personal (Facebook, Twitter, Instagram)	86.36%	19
Interactive video (Skype, Facetime)	4.55%	1
Other	0.00%	0
None	9.09%	2
TOTAL		22

Q22: Why did you select these tools for LEAST PREFERRED support? (Check all that apply)

ANSWER CHOICES	RESPONSES	
Employer policy	27.27%	6
Security	54.55%	12
Professional best practice	45.45%	10
Legal requirements	27.27%	6
Licensing requirements	13.64%	3
Fear of information misuse	63.64%	14
Empathy for patient/caregiver convenience	27.27%	6
Total Respondents: 22		

Q24: Is there a difference between social media and professional portal online discussions as a resource for patient caregiver information?

ANSWER CHOICES	RESPONSES	
Yes	94.74%	18
No	5.26%	1
TOTAL		19

Q26: What is your PERSONAL MOST PREFERRED tool to communicate?

ANSWER CHOICES	RESPONSES	
Email/text	89.47%	17
Facebook	0.00%	0
WhatsApp	0.00%	0
Twitter	0.00%	0
Instagram	0.00%	0
Snapchat	0.00%	0
Other	10.53%	2
None	0.00%	0
TOTAL		19

Q27: What is your PROFESSIONAL MOST PREFERRED tool to communicate?

ANSWER CHOICES	RESPONSES	
Email/text	63.16%	12
Facebook	0.00%	0
WhatsApp	0.00%	0
Twitter	0.00%	0
Instagram	0.00%	0
Snapchat	0.00%	0
Other	26.32%	5
None	10.53%	2
TOTAL		19

Q29: In your opinion, is social media ...

	YES	NO	SOMETIMES	TOTAL	WEIGHTED AVERAGE
safe and secure for professional communication?	0.00% 0	78.95% 15	21.05% 4	19	2.21
safe and secure for personal communication?	5.26% 1	42.11% 8	52.63% 10	19	2.47
reliable for sharing facts in medical practice?	5.26% 1	57.89% 11	36.84% 7	19	2.32
reliable for sharing opinions in medical practice?	15.79% 3	36.84% 7	47.37% 9	19	2.32
effective for sharing facts in medical practice?	26.32% 5	47.37% 9	26.32% 5	19	2.00
effective for sharing opinions in medical practice?	26.32% 5	36.84% 7	36.84% 7	19	2.11

Q30: Appropriate Social Media Information Sharing (1-7 scale, 1 being the least)

	1	2	3	4	5	6	7	TOTAL
Diagnosis	64.71% 11	5.88% 1	0.00% 0	5.88% 1	11.76% 2	11.76% 2	0.00% 0	17
Treatment	58.82% 10	11.76% 2	0.00% 0	5.88% 1	11.76% 2	11.76% 2	0.00% 0	17
Care plan	58.82% 10	11.76% 2	5.88% 1	0.00% 0	17.65% 3	5.88% 1	0.00% 0	17
Medical status	58.82% 10	5.88% 1	5.88% 1	5.88% 1	5.88% 1	11.76% 2	5.88% 1	17
Cost of care	58.82% 10	5.88% 1	17.65% 3	0.00% 0	11.76% 2	5.88% 1	0.00% 0	17
Insurance	52.94% 9	11.76% 2	5.88% 1	11.76% 2	11.76% 2	5.88% 1	0.00% 0	17
Social networking	23.53% 4	0.00% 0	5.88% 1	5.88% 1	5.88% 1	29.41% 5	29.41% 5	17
Community interactive meetings	17.65% 3	5.88% 1	0.00% 0	5.88% 1	11.76% 2	29.41% 5	29.41% 5	17
Community online discussions	11.76% 2	11.76% 2	0.00% 0	11.76% 2	11.76% 2	29.41% 5	23.53% 4	17
Counseling	29.41% 5	17.65% 3	17.65% 3	11.76% 2	5.88% 1	17.65% 3	0.00% 0	17
Other psychosocial support	11.76% 2	17.65% 3	11.76% 2	29.41% 5	17.65% 3	11.76% 2	0.00% 0	17
Referral services	29.41% 5	0.00% 0	23.53% 4	11.76% 2	17.65% 3	11.76% 2	5.88% 1	17
Case studies	41.18% 7	0.00% 0	11.76% 2	5.88% 1	11.76% 2	23.53% 4	5.88% 1	17
Research studies	35.29% 6	0.00% 0	17.65% 3	0.00% 0	11.76% 2	17.65% 3	17.65% 3	17
Appointment information	58.82% 10	11.76% 2	0.00% 0	17.65% 3	0.00% 0	5.88% 1	5.88% 1	17
Medication side effects	35.29% 6	11.76% 2	5.88% 1	17.65% 3	23.53% 4	5.88% 1	0.00% 0	17
Hospital admission instructions	41.18% 7	11.76% 2	11.76% 2	11.76% 2	17.65% 3	0.00% 0	5.88% 1	17
Hospital discharge instructions	41.18% 7	17.65% 3	11.76% 2	5.88% 1	17.65% 3	0.00% 0	5.88% 1	17

Appendix E: Websites Investigated

A visual summary of the websites investigated is provided below and each is listed in the References section.

National Institute of Health (NIH) Comprehensive & Cancer Care Centers

University of Alabama at Birmingham	Knight Cancer Institute
University of Arizona	Hollings Cancer Center
Children's Hospital Colorado	St. Jude Children's Research Hospital
Yale University School of Medicine	Vanderbilt-Ingram Cancer Center
Georgetown Lombardi Comprehensive Cancer Center	Huntsman Cancer Institute
Moffitt Cancer Center	Massey Cancer Center
Winship Cancer Institute	University of Virginia Cancer Center
University of Hawaii Cancer Center	Fred Hutchinson/University of Washington Cancer Consortium
Robert H. Lurie Comprehensive Cancer Center	University of Wisconsin Carbone Cancer Center
The University of Chicago Comprehensive Cancer Center	Dan L Duncan Comprehensive Cancer Center
Indiana University Melvin and Bren Simon Cancer Center	Mays Cancer Center at UT Health San Antonio
Holden Comprehensive Cancer Center	Harold C. Simmons Comprehensive Cancer Center
The University of Kansas Cancer Center	The University of Texas MD Anderson Cancer Center
Markey Cancer Center	Abramson Cancer Center
Sidney Kimmel Comprehensive Cancer Center	UPMC Hillman Cancer Center
University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center	Fox Chase Cancer Center
Dana-Farber/Harvard Cancer Center	Sidney Kimmel Cancer Center at Thomas Jefferson University
The Barbara Ann Karmanos Cancer Institute	Albert Einstein Cancer Center
Dana Farber/Boston Children's Hospital	Memorial Sloan-Kettering Cancer Center
University of Michigan Rogel Cancer Center	Roswell Park Comprehensive Cancer Center
Masonic Cancer Center	Herbert Irving Comprehensive Cancer Center
Mayo Clinic Cancer Center	The Tisch Cancer Institute at Mount Sinai
Alvin J. Siteman Cancer Center	Laura and Isaac Perlmutter Cancer Center at NYU Langone Health
Fred and Pamela Buffett Cancer Center	Chao Family Comprehensive Cancer Center
Norris Cotton Cancer Center at Dartmouth	Stanford Cancer Institute (SCI)
Rutgers Cancer Institute of New Jersey	City of Hope Comprehensive Cancer Center
University of New Mexico Cancer Center	UC Davis Comprehensive Cancer Center
Duke Cancer Institute	Jonsson Comprehensive Cancer Center
Wake Forest Baptist Comprehensive Cancer Center	UC San Diego Moores Cancer Center
UNC Lineberger Comprehensive Cancer Center	UCSF Helen Diller Family Comprehensive Cancer Center
Case Comprehensive Cancer Center	USC Norris Comprehensive Cancer Center
The Ohio State University Comprehensive Cancer Center	Dana-Farber Cancer Institute
Stephenson Cancer Center	Boston Children's Hospital

Not-for-profits with pediatric oncology psycho-social support services

Alex's Lemonade Stand Foundation	Make A Wish
American Cancer Society	Mikey's Way Foundation
American Childhood Cancer Organization	National Cancer Institute
Art from the Heart	National Coalition for Cancer Survivorship
ASK Childhood Cancer Foundation	National Pediatric Cancer Foundation
Brady's Smile	Pediatric Cancer Awareness 24/7
Camp Rising Sun	Pediatric Cancer Foundation
Camp Sunshine	Pediatric Cancer Networking
Cancer Survivors Network	Pediatric Oncology Resource Center
CancerCare	Songs of Love Foundation
Caringbridge	Springboard Beyond Cancer
Chai Lifeline	Stand Up To Cancer
Children's Brain Tumor Foundation	Supersibs
Children's Oncology Camping Association, International	The Compassionate Friends
Circle of Care	The Leukemia & Lymphoma Society
Circle of Care Parents Facebook Group	The National Children's Cancer Society
Curesearch for Childhood Cancer	Whip Pediatric Cancer

(Abramson Cancer Center, 2019; Albert Einstein Cancer Center, 2019; Alex's Lemonade Stand Foundation, 2019a, 2019b, 2019c, 2019d, 2019e, 2019f, 2020; Alvin J. Siteman Cancer Center, 2019; American Cancer Society, 2019; American Childhood Cancer Organization, 2020; ASK Childhood Cancer Foundation, 2019, 2020; Belong.Life, 2019; Boston Childrens Hospital, 2019; Brady's Smile, 2019; Camp Rising Sun, 2019; Camp Sunshine, 2019; CancerCare, 2019, 2020; Caring Bridge; Caringbridge, 2019; Case Comprehensive Cancer Center, 2019; T. O. S. U. C. C. Center, 2019; T. W. I. C. Center, 2019; Chai Lifeline, 2019; Chao Family Comprehensive Cancer Center, 2019; Childhood Cancer Data Initiative; Children's Oncology Camping Association International, 2019; Children's Brain Tumor Foundation, 2019, 2020; Children's Oncology Camping Association; Circle of Care, 2019a, 2019b; City of Hope Comprehensive Cancer Center, 2019, 2020; Cold Spring Harbor Laboratory Cancer Center, 2019; Cure Childhood Cancer; Dan L Duncan Comprehensive Cancer Center, 2019; Dana-Farber Cancer Institute, 2019; Dana-Farber/Harvard Cancer Center, 2019; Dana Farber/Boston Children's Hospital, 2019a, 2019b, 2019c; David H. Koch Institute for Integrative Cancer Research at MIT, 2019; Duke Cancer Institute Pediatric Cancer, 2019; Foundation & 2019; Fox Chase Cancer Center, 2019; Fred and Pamela Buffett Cancer Center, 2019; Fred Hutchinson/University of Washington Cancer Consortium, 2019; George Washington University; Harold C. Simmons Comprehensive Cancer Center, 2019; Herbert Irving Comprehensive Cancer Center, 2019; Hillman Cancer Center, 2019; Holden Comprehensive Cancer Center, 2019; Hollings Cancer Center, 2019a, 2019b; Huntsman Cancer Institute, 2019; Indiana University Melvin and Bren Simon Cancer Center, 2019; Inspire.com, 2020; Jonsson Comprehensive Cancer Center, 2019; Knight Cancer Institute, 2019a, 2019b; Laura and Isaac Perlmutter Cancer Center at NYU Langone Health, 2019; Leukemia and Lymphoma Society; Lotsa Helping Hands, 2019; Markey Cancer Center, 2019; Masonic Cancer Center, 2019; Massey Cancer Center, 2019; Mayo Clinic Cancer Center, 2019a, 2019b; Mays Cancer Center at UT Health San Antonio, 2019; Memorial Sloan-Kettering Cancer Center, 2019a, 2019b, 2019c, 2020a, 2020b; Mikey's Way Foundation, 2019; Moffitt Cancer Center, 2019; Momcologist Foundation; National Cancer Institute, 2019; National Coalition for Cancer Survivorship; National Information Center on Health Services Research & Health Care Technology, 2018, 2019, 2020; National Institute of Health; National Pediatric Cancer Foundation; Norris Cotton Cancer Center at Dartmouth, 2019; Patient-Centered Outcomes Research Institute; Patients Like Me, 2019; Pediatric Cancer Awareness 24/7, 2019; Pediatric Cancer Foundation, 2019; Pediatric Cancer Networking, 2019; Pediatric Oncology Resource Center, 2019; Purdue University, 2019; Robert H. Lurie Comprehensive Cancer Center, 2019, 2020; Roswell Park Cancer Center, 2020; Roswell Park Comprehensive Cancer, 2020; Roswell Park Comprehensive Cancer Center, 2019; Rutgers Cancer Institute of New Jersey, 2019a, 2019b; Salk Institute Cancer Center, 2019; Sanford Burnham Prebys Medical Discovery Institute, 2019; Sidney Kimmel Cancer Center at Thomas Jefferson University, 2019, 2020; Sidney Kimmel Comprehensive Cancer, 2020; Sidney Kimmel Comprehensive Cancer Center, 2019a, 2019b, 2019c, 2019d, 2019e, 2019f, 2019g, 2019h; Society, 2019; Songs of Love Foundation, 2019;

Springboard Beyond Cancer, 2019; St. Jude Children's Research Hospital, 2019a, 2019b, 2019c, 2019d; Stand Up To Cancer, 2019; Stanford Cancer Institute (SCI), 2019; Stephenson Cancer Center, 2019; The Barbara Ann Karmanos Cancer Institute, 2019a, 2019b; The Compassionate Friends, 2019; The Jackson Laboratory Cancer Center, 2019; The Leukemia & Lymphoma Society, 2019; The National Children's Cancer Society, 2019, 2020a, 2020b; The Ohio State University Comprehensive Cancer Center, 2019; The Tisch Cancer Institute at Mount Sinai, 2019; The University of Chicago Comprehensive Cancer Center, 2019a, 2019b; The University of Kansas Cancer Center, 2019; The University of Texas MD Anderson Cancer Center, 2019; UC Davis Comprehensive Cancer Center, 2019, 2020; UC San Diego Moores Cancer Center, 2019; UCSF Helen Diller Family Comprehensive Cancer Center, 2019; UNC Lineberger Comprehensive Cancer Center, 2019; University of Hawaii Cancer Center, 2019; University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center, 2019a, 2019b; University of Michigan Rogel Cancer Center, 2019; University of New Mexico Cancer Center, 2019; University of Virginia Cancer Center, 2019; University of Wisconsin Carbone Cancer Center, 2019; USC Norris Comprehensive Cancer Center, 2019a, 2019b; Vanderbilt-Ingram Cancer Center, 2019a, 2019b, 2019c; Wake Forest Baptist Comprehensive Cancer Center, 2019a, 2019b; WebMD; Weibo.com, 2020; Whip Pediatric Cancer, 2019; Winship Cancer Institute, 2019; World Health Organization; Yale Pediatric Hematology-Oncology)

Appendix F: Website Data

Website data is available in the accompanied electronic file (APPENDIX-Website Data Collection-11Aug2019).

Note: In the below data coding of 1=Yes and 0=No.

ID	Organization Name
100	Make A Wish
101	Make A Wish
102	Circle of Care
103	American Childhood Cancer Organization
104	American Childhood Cancer Organization
105	American Childhood Cancer Organization
106	American Childhood Cancer Organization
107	American Childhood Cancer Organization
108	American Childhood Cancer Organization
109	American Childhood Cancer Organization
110	American Childhood Cancer Organization
111	American Childhood Cancer Organization
112	American Childhood Cancer Organization
113	American Childhood Cancer Organization
114	American Childhood Cancer Organization
115	American Childhood Cancer Organization

116	American Childhood Cancer Organization
117	American Childhood Cancer Organization
118	American Childhood Cancer Organization
119	American Childhood Cancer Organization
120	American Cancer Society
121	American Cancer Society
122	American Cancer Society
123	American Cancer Society
124	American Cancer Society
125	American Cancer Society
126	American Cancer Society
127	American Cancer Society
128	American Cancer Society
129	American Cancer Society
130	American Cancer Society
131	American Cancer Society
132	American Cancer Society
133	American Cancer Society
134	American Cancer Society
135	University of Alabama at Birmingham
136	University of Alabama at Birmingham
137	University of Alabama at Birmingham
138	University of Alabama at Birmingham
139	University of Alabama at Birmingham

140	University of Arizona
141	Children's Hospital Colorado
142	Yale University School of Medicine
143	Georgetown Lombardi Comprehensive Cancer Center
144	Georgetown Lombardi Comprehensive Cancer Center
145	Georgetown Lombardi Comprehensive Cancer Center
146	Georgetown Lombardi Comprehensive Cancer Center
147	Curesearch for Childhood Cancer
148	Curesearch for Childhood Cancer
149	Curesearch for Childhood Cancer
150	Curesearch for Childhood Cancer
151	Curesearch for Childhood Cancer
152	Curesearch for Childhood Cancer
153	Curesearch for Childhood Cancer
154	National Coalition for Cancer Survivorship
155	National Coalition for Cancer Survivorship
156	Moffitt Cancer Center
157	Winship Cancer Institute
158	University of Hawaii Cancer Center
159	Pediatric Oncology Resource Center
160	Cancer Survivors Network
161	American Cancer Society
162	Springboard Beyond Cancer
163	Belong.Life

164	Robert H. Lurie Comprehensive Cancer Center
165	The University of Chicago Comprehensive Cancer Center
166	The University of Chicago Comprehensive Cancer Center
167	Indiana University Melvin and Bren Simon Cancer Center
168	Purdue University Center for Cancer Research
169	Holden Comprehensive Cancer Center
170	The University of Kansas Cancer Center
171	Markey Cancer Center
172	The Jackson Laboratory Cancer Center
173	Sidney Kimmel Comprehensive Cancer Center
174	Sidney Kimmel Comprehensive Cancer Center
175	Sidney Kimmel Comprehensive Cancer Center
176	Sidney Kimmel Comprehensive Cancer Center
177	Sidney Kimmel Comprehensive Cancer Center
178	Sidney Kimmel Comprehensive Cancer Center
179	Sidney Kimmel Comprehensive Cancer Center
180	Sidney Kimmel Comprehensive Cancer Center
181	University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center
182	University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center
183	Dana-Farber/Harvard Cancer Center
184	David H. Koch Institute for Integrative Cancer Research at MIT
185	The Barbara Ann Karmanos Cancer Institute
186	The Barbara Ann Karmanos Cancer Institute

187	Dana Farber/Boston Children's Hospital
188	Dana Farber/Boston Children's Hospital
189	Dana Farber/Boston Children's Hospital
190	University of Michigan Rogel Cancer Center
191	Masonic Cancer Center
192	Mayo Clinic Cancer Center
193	Mayo Clinic Cancer Center
194	Alvin J. Siteman Cancer Center
195	Fred and Pamela Buffett Cancer Center
196	Norris Cotton Cancer Center at Dartmouth
197	Rutgers Cancer Institute of New Jersey
198	Rutgers Cancer Institute of New Jersey
199	University of New Mexico Cancer Center
200	Duke Cancer Institute
201	Wake Forest Baptist Comprehensive Cancer Center
202	Wake Forest Baptist Comprehensive Cancer Center
203	UNC Lineberger Comprehensive Cancer Center
204	Case Comprehensive Cancer Center
205	The Ohio State University Comprehensive Cancer Center
206	The Ohio State University Comprehensive Cancer Center
207	Stephenson Cancer Center
208	Knight Cancer Institute
209	Knight Cancer Institute
210	Hollings Cancer Center

211	Hollings Cancer Center
212	St. Jude Children's Research Hospital
213	St. Jude Children's Research Hospital
214	St. Jude Children's Research Hospital
215	St. Jude Children's Research Hospital
216	Vanderbilt-Ingram Cancer Center
217	Vanderbilt-Ingram Cancer Center
218	Vanderbilt-Ingram Cancer Center
219	Huntsman Cancer Institute
220	ASK Childhood Cancer Foundation
221	Massey Cancer Center
222	University of Virginia Cancer Center
223	Fred Hutchinson/University of Washington Cancer Consortium
224	University of Wisconsin Carbone Cancer Center
225	Dan L Duncan Comprehensive Cancer Center
226	Mays Cancer Center at UT Health San Antonio
227	Harold C. Simmons Comprehensive Cancer Center
228	The University of Texas MD Anderson Cancer Center
229	Abramson Cancer Center
230	UPMC Hillman Cancer Center
231	Fox Chase Cancer Center
232	The Wistar Institute Cancer Center
233	Sidney Kimmel Cancer Center at Thomas Jefferson University
234	Albert Einstein Cancer Center

235	Memorial Sloan-Kettering Cancer Center
236	Memorial Sloan-Kettering Cancer Center
237	Memorial Sloan-Kettering Cancer Center
238	Cold Spring Harbor Laboratory Cancer Center
239	Roswell Park Comprehensive Cancer Center
240	Herbert Irving Comprehensive Cancer Center
241	The Tisch Cancer Institute at Mount Sinai
242	Laura and Isaac Perlmutter Cancer Center at NYU Langone Health
243	Chao Family Comprehensive Cancer Center
244	Stanford Cancer Institute (SCI)
245	City of Hope Comprehensive Cancer Center
246	UC Davis Comprehensive Cancer Center
247	Jonsson Comprehensive Cancer Center
248	UC San Diego Moores Cancer Center
249	Salk Institute Cancer Center
250	UCSF Helen Diller Family Comprehensive Cancer Center
251	Sanford Burnham Prebys Medical Discovery Institute
252	USC Norris Comprehensive Cancer Center
253	USC Norris Comprehensive Cancer Center
254	Caringbridge
255	Circle of Care Parents Facebook Group
256	Pediatric Cancer Awareness 24/7
257	National Pediatric Cancer Foundation
258	Whip Pediatric Cancer

259	Pediatric Cancer Foundation
260	Pediatric Cancer Networking
261	Dana-Farber Cancer Institute
262	Boston Childrens Hospital
263	The Leukemia & Lymphoma Society
264	Camp Rising Sun
265	Stand Up To Cancer
266	Lotsa Helping Hands
267	Art from the Heart
268	Supersibs
269	Alex's Lemonade Stand Foundation
270	Alex's Lemonade Stand Foundation
271	Alex's Lemonade Stand Foundation
272	Alex's Lemonade Stand Foundation
273	Alex's Lemonade Stand Foundation
274	The Compassionate Friends
275	Chai Lifeline
276	Camp Sunshine
277	National Cancer Institute
278	Children's Oncology Camping Association, International
279	Children’s Brain Tumor Foundation
280	Songs of Love Foundation
281	Mikey’s Way Foundation
282	Brady's Smile

283	CancerCare
284	The National Children's Cancer Society
285	The National Children's Cancer Society
286	Patients Like Me

ID	NIH supported	Sector	Non-medical Support Service	Restricted to affiliated patients / families	Serve as portal / gateway
100	0	Not-for-profit	1	0	0
101	0	Not-for-profit	1	0	0
102	0	Not-for-profit	1	0	1
103	0	Not-for-profit	1	1	1
104	0	Not-for-profit	1	1	0
105	0	Not-for-profit	1	1	0
106	0	Not-for-profit	1	1	0
107	0	Not-for-profit	1	1	0
108	0	Not-for-profit	1	1	0
109	0	Not-for-profit	1	1	0
110	0	Not-for-profit	1	1	0
111	0	Not-for-profit	1	1	0
112	0	Not-for-profit	1	1	0
113	0	Not-for-profit	1	1	0
114	0	Not-for-profit	1	1	0

115	0	Not-for-profit	1	1	0
116	0	Not-for-profit	1	1	0
117	0	Not-for-profit	1	1	0
118	0	Not-for-profit	1	1	0
119	0	Not-for-profit	1	0	0
120	0	Not-for-profit	1	0	1
121	0	Not-for-profit	1	0	1
122	0	Not-for-profit	1	0	1
123	0	Not-for-profit	1	0	1
124	0	Not-for-profit	1	0	1
125	0	Not-for-profit	1	0	1
126	0	Not-for-profit	1	0	1
127	0	Not-for-profit	1	0	1
128	0	Not-for-profit	1	0	1
129	0	Not-for-profit	1	0	1
130	0	Not-for-profit	1	0	1
131	0	Not-for-profit	1	0	1
132	0	Not-for-profit	1	0	1
133	0	Not-for-profit	1	0	1
134	0	Not-for-profit	1	0	1
135	1	University	1	0	1
136	1	University	1	0	1
137	1	University	1	0	1
138	1	University	1	0	1

139	1	University	1	0	1
140	1	University	1	1	0
141	1	University	1	0	1
142	1	University	1	1	0
143	1	University	1	1	0
144	1	University	1	1	0
145	1	University	1	1	0
146	1	University	1	1	0
147	0	Not-for-profit	1	0	0
148	0	Not-for-profit	1	0	0
149	0	Not-for-profit	1	0	0
150	0	Not-for-profit	1	0	0
151	0	Not-for-profit	1	0	0
152	0	Not-for-profit	1	0	0
153	0	Not-for-profit	1	0	0
154	0	Not-for-profit	1	0	0
155	0	Not-for-profit	1	0	0
156	1	Not-for-profit	1	1	0
157	1	University	1	0	0
158	1	University	0	0	0
159	0	Not-for-profit	1	0	1
160	0	Not-for-profit	1	0	1
161	0	Not-for-profit	1	0	0
162	0	Government	1	0	0

163	0	For-Profit	1	0	0
164	1	University	1	1	0
165	1	University	1	0	0
166	1	University	1	0	0
167	1	University	1	0	0
168	1	University	0	0	0
169	1	University	1	0	0
170	1	Not-for-profit	1	0	0
171	1	University	1	0	0
172	1	Not-for-profit	0	0	0
173	1	University	1	0	1
174	1	University	1	0	1
175	1	University	1	1	0
176	1	University	1	1	0
177	1	University	1	0	0
178	1	University	1	1	1
179	1	University	1	1	0
180	1	University	1	1	0
181	1	University	1	0	1
182	1	University	1	0	1
183	1	University	1	0	1
184	1	University	0	0	0
185	1	Not-for-profit	1	1	1
186	1	Not-for-profit	1	0	1

187	1	University	1	0	1
188	1	University	1	0	1
189	1	University	1	1	1
190	1	University	1	0	1
191	1	University	1	1	0
192	1	Not-for-profit	1	0	1
193	1	Not-for-profit	1	0	1
194	1	University	1	1	1
195	1	Not-for-profit	1	1	1
196	1	University	1	0	1
197	1	University	1	0	1
198	1	University	1	0	1
199	1	University	1	0	0
200	1	University	1	0	0
201	1	University	1	0	0
202	1	University	1	1	0
203	1	University	1	1	0
204	1	University	1	0	0
205	1	University	1	0	0
206	1	University	1	0	1
207	1	Not-for-profit	1	0	0
208	1	University	1	0	0
209	1	University	1	0	0
210	1	University	1	0	0

211	1	University	1	0	0
212	1	Not-for-profit	1	0	1
213	1	Not-for-profit	1	0	1
214	1	Not-for-profit	1	0	1
215	1	Not-for-profit	1	0	1
216	1	University	1	0	0
217	1	University	1	0	0
218	1	University	1	0	0
219	1	University	1	0	1
220	0	Not-for-profit	1	1	1
221	1	Not-for-profit	1	0	0
222	1	University	1	0	0
223	1	University	1	0	1
224	1	University	1	0	1
225	1	University	1	0	1
226	1	University	1	0	0
227	1	University	1	0	0
228	1	University	1	0	1
229	1	University	1	0	0
230	1	University	1	0	1
231	1	Not-for-profit	1	0	0
232	1	Not-for-profit	0	0	0
233	1	University	1	1	0
234	1	University	1	0	1

235	1	Not-for-profit	1	1	1
236	1	University	1	0	1
237	1	University	1	1	1
238	1	University	0	0	0
239	1	University	1	1	1
240	1	University	1	0	0
241	1	University	1	0	0
242	1	University	1	0	0
243	1	University	1	0	0
244	1	University	1	0	0
245	1	University	1	1	0
246	1	University	1	1	1
247	1	University	1	0	0
248	1	University	1	0	0
249	1	University	0	0	0
250	1	University	1	0	0
251	1	Not-for-profit	0	0	0
252	1	University	1	0	0
253	1	University	1	0	0
254	0	Not-for-profit	1	1	0
255	0	For-Profit	1	0	1
256	0	For-Profit	1	0	1
257	0	For-Profit	1	0	1
258	0	For-Profit	1	0	1

259	0	For-Profit	1	0	1
260	0	For-Profit	1	0	1
261	1	For-Profit	1	0	1
262	0	For-Profit	1	0	1
263	0	For-Profit	1	0	1
264	0	For-Profit	1	0	1
265	0	For-Profit	1	0	1
266	0	For-Profit	1	0	0
267	0	Not-for-profit	1	1	0
268	0	Not-for-profit	1	1	0
269	0	Not-for-profit	1	1	1
270	0	Not-for-profit	1	1	
271	0	Not-for-profit	1	1	
272	0	Not-for-profit	1	1	
273	0	Not-for-profit	1	1	1
274	0	Not-for-profit	1	1	1
275	0	Not-for-profit	1	1	1
276	0	Not-for-profit	1	1	0
277	0	Government	1	1	1
278	0	Not-for-profit	1	1	1
279	0	Not-for-profit	1	1	1
280	0	Not-for-profit	1	1	0
281	0	Not-for-profit	1	1	0
282	0	Not-for-profit	1	1	0

283	0	Not-for-profit	1	1	1
284	0	Not-for-profit	1	1	1
285	0	Not-for-profit	1	1	1
286	0	For-Profit	1	1	1

ID	**Category**	**Sub-category**	**Service Classification**	**Format**
100	Discussion-personal	Story - single broadcast	Interpersonal	Other deliverable
101	Information-electronic document	Blog - series of stories	Interpersonal	Other deliverable
102	Information-electronic link	Not recorded	Interpersonal	Website
103	Information-electronic link	Forum - interactive	Patient Perspective	Website
104	Discussion-forum	Forum - interactive	Patient Perspective	Application
105	Discussion-forum	Forum - interactive	Patient Perspective	Application
106	Discussion-forum	Forum - interactive	Patient Perspective	Application
107	Discussion-forum	Forum - interactive	Patient Perspective	Application
108	Discussion-forum	Forum - interactive	Patient Perspective	Application
109	Discussion-forum	Forum - interactive	Patient Perspective	Application

110	Discussion-forum	Forum - interactive	Patient Perspective	Application
111	Discussion-forum	Forum - interactive	Patient Perspective	Application
112	Discussion-forum	Forum - interactive	Patient Perspective	Application
113	Discussion-forum	Forum - interactive	Patient Perspective	Application
114	Discussion-forum	Forum - interactive	Patient Perspective	Application
115	Discussion-forum	Forum - interactive	Patient Perspective	Application
116	Discussion-forum	Forum - interactive	Patient Perspective	Application
117	Discussion-forum	Forum - interactive	Patient Perspective	Application
118	Discussion-forum	Forum - interactive	Patient Perspective	Application
119	Information-physical copy	Not recorded	Patient Perspective	Other deliverable
120	Information-electronic link	Not recorded	Patient Perspective	Website
121	Information-electronic link	Not recorded	Financial	Website
122	Information-electronic link	Not recorded	Technical	Website
123	Information-electronic link	Not recorded	Patient Perspective	Website
124	Information-electronic link	Not recorded	Interpersonal	Website

125	Information-electronic link	Not recorded	Patient Perspective	Website
126	Information-electronic link	Not recorded	Interpersonal	Website
127	Information-electronic link	Not recorded	Patient Perspective	Website
128	Information-electronic link	Not recorded	Interpersonal	Website
129	Information-electronic link	Not recorded	Technical	Website
130	Information-electronic link	Not recorded	Technical	Website
131	Information-electronic link	Not recorded	Technical	Website
132	Information-electronic link	Not recorded	Interpersonal	Website
133	Information-electronic link	Not recorded	Financial	Website
134	Information-electronic link	Not recorded	Patient Perspective	Website
135	Information-physical copy	Not recorded	Patient Perspective	Other deliverable
136	Information-electronic link	Not recorded	Patient Perspective	Website
137	Information-electronic document	Not recorded	Patient Perspective	Website
138	Information-electronic link	Not recorded	Patient Perspective	Other deliverable
139	Discussion-personal	Not recorded	Patient Perspective	Discussion

140	Discussion-personal	Not recorded	Technical	Discussion
141	Information-electronic link	Not recorded	Patient Perspective	Website
142	Discussion-personal	Not recorded	Technical	Discussion
143	Information-electronic document	Not recorded	Patient Perspective	Website
144	Information-electronic document	Not recorded	Technical	Website
145	Information-electronic document	Not recorded	Technical	Website
146	Information-electronic document	Not recorded	Patient Perspective	Website
147	Discussion-personal	Story - single broadcast	Interpersonal	Other deliverable
148	Discussion-personal	Story - single broadcast	Interpersonal	Application
149	Discussion-personal	Forum - interactive	Interpersonal	Application
150	Information-electronic document	Story - single broadcast	Interpersonal	Application
151	Discussion-personal	Forum - interactive	Interpersonal	Application
152	Information-electronic document	Forum - interactive	Patient Perspective	Application
153	Discussion-personal	Forum - interactive	Patient Perspective	Application
154	Discussion-personal	Forum - interactive	Interpersonal	Application
155	Information-electronic document	Story - single broadcast	Organizational	Website
156	Discussion-personal	Not recorded	Organizational	Discussion

157	Discussion-personal	Not recorded	Organizational	Discussion
158	Discussion-forum	Forum - interactive	Organizational	Discussion
159	Information-electronic link	Not recorded	Patient Perspective	Website
160	Discussion-forum	Forum - interactive	Patient Perspective	Application
161	Information-electronic link	Not recorded	Interpersonal	Website
162	Discussion-forum	Forum - interactive	Patient Perspective	Other deliverable
163	Discussion-forum	Forum - interactive	Patient Perspective	Application
164	Discussion-personal	Not recorded	Patient Perspective	Discussion
165	Information-physical copy	Not recorded	Patient Perspective	Other deliverable
166	Discussion-personal	Not recorded	Patient Perspective	Discussion
167	Information-physical copy	Not recorded	Patient Perspective	Discussion
168	Information-physical copy	Not recorded	Research	Other deliverable
169	Discussion-personal	Not recorded	Organizational	Other deliverable
170	Discussion-personal	Not recorded	Patient Perspective	Other deliverable
171	Discussion-personal	Not recorded	Organizational	Other deliverable

172	Information-physical copy	Not recorded	Research	Other deliverable
173	Information-electronic link	Blog - series of stories	Interpersonal	Other deliverable
174	Information-electronic link	Not recorded	Patient Perspective	Website
175	Information-physical copy	Not recorded	Patient Perspective	Other deliverable
176	Information-electronic document	Not recorded	Technical	Website
177	Information-electronic link	Not recorded	Patient Perspective	Website
178	Information-electronic link	Not recorded	Patient Perspective	Website
179	Information-electronic link	Not recorded	Patient Perspective	Website
180	Information-electronic link	Not recorded	Technical	Website
181	Information-electronic link	Not recorded	Patient Perspective	Website
182	Information-electronic link	Story - single broadcast	Patient Perspective	Website
183	Information-electronic link	Not recorded	Technical	Website
184	Information-physical copy	Not recorded	Research	Other deliverable
185	Discussion-forum	Forum - interactive	Patient Perspective	Application
186	Information-electronic link	Not recorded	Interpersonal	Website

187	Information-electronic link	Not recorded	Interpersonal	Website
188	Information-electronic document	Not recorded	Technical	Website
189	Information-electronic link	Not recorded	Technical	Website
190	Information-electronic link	Not recorded	Technical	Website
191	Information-electronic link	Not recorded	Technical	Website
192	Discussion-forum	Forum - interactive	Patient Perspective	Application
193	Discussion-forum	Forum - interactive	Patient Perspective	Application
194	Information-electronic document	Not recorded	Organizational	Website
195	Information-electronic link	Not recorded	Organizational	Website
196	Information-electronic document	Not recorded	Organizational	Website
197	Information-electronic document	Not recorded	Organizational	Website
198	Information-electronic document	Not recorded	Patient Perspective	Discussion
199	Discussion-personal	Not recorded	Patient Perspective	Discussion
200	Discussion-personal	Not recorded	Patient Perspective	Discussion
201	Discussion-personal	Not recorded	Patient Perspective	Discussion

202	Discussion-personal	Not recorded	Patient Perspective	Website
203	Discussion-personal	Not recorded	Patient Perspective	Website
204	Information-physical copy	Not recorded	Patient Perspective	Website
205	Discussion-personal	Not recorded	Patient Perspective	Other deliverable
206	Discussion-personal	Not recorded	Patient Perspective	Discussion
207	Discussion-forum	Forum - interactive	Interpersonal	Discussion
208	Discussion-personal	Not recorded	Patient Perspective	Discussion
209	Discussion-personal	Not recorded	Patient Perspective	Discussion
210	Discussion-personal	Not recorded	Patient Perspective	Discussion
211	Discussion-personal	Not recorded	Patient Perspective	Discussion
212	Discussion-personal	Not recorded	Patient Perspective	Website
213	Information-electronic document	Not recorded	Patient Perspective	Application
214	Information-electronic document	Not recorded	Patient Perspective	Application
215	Information-electronic document	Not recorded	Patient Perspective	Website
216	Discussion-personal	Not recorded	Patient Perspective	Discussion

217	Discussion-personal	Not recorded	Patient Perspective	Discussion
218	Discussion-personal	Not recorded	Patient Perspective	Discussion
219	Discussion-personal	Not recorded	Patient Perspective	Discussion
220	Discussion-personal	Not recorded	Patient Perspective	Website
221	Discussion-personal	Not recorded	Patient Perspective	Discussion
222	Discussion-personal	Not recorded	Patient Perspective	Discussion
223	Discussion-personal	Not recorded	Patient Perspective	Discussion
224	Discussion-personal	Not recorded	Patient Perspective	Discussion
225	Discussion-personal	Not recorded	Patient Perspective	Discussion
226	Discussion-personal	Not recorded	Patient Perspective	Discussion
227	Discussion-personal	Not recorded	Patient Perspective	Discussion
228	Discussion-personal	Not recorded	Patient Perspective	Discussion
229	Discussion-personal	Not recorded	Patient Perspective	Discussion
230	Discussion-personal	Not recorded	Patient Perspective	Discussion
231	Discussion-personal	Not recorded	Patient Perspective	Discussion

232	Information-physical copy	Not recorded	Research	Other deliverable
233	Information-electronic document	Not recorded	Patient Perspective	Website
234	Information-electronic link	Not recorded	Patient Perspective	Website
235	Information-electronic link	Not recorded	Patient Perspective	Other deliverable
236	Discussion-personal	Not recorded	Patient Perspective	Discussion
237	Discussion-forum	Not recorded	Patient Perspective	Application
238	Information-physical copy	Not recorded	Research	Other deliverable
239	Information-electronic link	Not recorded	Patient Perspective	Discussion
240	Information-electronic document	Not recorded	Patient Perspective	Discussion
241	Discussion-personal	Not recorded	Patient Perspective	Discussion
242	Discussion-personal	Not recorded	Patient Perspective	Discussion
243	Discussion-personal	Not recorded	Patient Perspective	Discussion
244	Discussion-personal	Not recorded	Patient Perspective	Discussion
245	Discussion-personal	Not recorded	Patient Perspective	Discussion
246	Information-electronic document	Not recorded	Patient Perspective	Other deliverable

247	Discussion-personal	Not recorded	Patient Perspective	Discussion
248	Discussion-personal	Not recorded	Patient Perspective	Discussion
249	Information-physical copy	Not recorded	Research	Other deliverable
250	Discussion-personal	Not recorded	Patient Perspective	Discussion
251	Information-physical copy	Not recorded	Research	Other deliverable
252	Discussion-personal	Not recorded	Patient Perspective	Other deliverable
253	Discussion-personal	Not recorded	Patient Perspective	Other deliverable
254	Discussion-forum	Forum - interactive	Interpersonal	Website
255	Discussion-forum	Forum - interactive	Interpersonal	Application
256	Discussion-forum	Forum - interactive	Interpersonal	Application
257	Discussion-forum	Forum - interactive	Interpersonal	Application
258	Discussion-forum	Forum - interactive	Interpersonal	Application
259	Discussion-forum	Forum - interactive	Interpersonal	Application
260	Discussion-forum	Forum - interactive	Interpersonal	Application
261	Discussion-forum	Forum - interactive	Interpersonal	Application
262	Discussion-forum	Forum - interactive	Interpersonal	Application
263	Discussion-forum	Forum - interactive	Interpersonal	Application
264	Discussion-forum	Forum - interactive	Interpersonal	Application
265	Discussion-forum	Forum - interactive	Interpersonal	Application

266	Information-electronic document	Not recorded	Interpersonal	Application
267	Information-physical copy	Not recorded	Interpersonal	Other deliverable
268	Information-electronic document	Forum - interactive	Interpersonal	Other deliverable
269	Information-electronic link	Not recorded	Financial	Website
270	Information-electronic document	Not recorded	Patient Perspective	Other deliverable
271	Information-electronic document	Not recorded	Patient Perspective	Other deliverable
272	Information-electronic document	Story - single broadcast	Patient Perspective	Other deliverable
273	Information-electronic link	Not recorded	Patient Perspective	Website
274	Information-electronic link	Not recorded	Patient Perspective	Website
275	Information-electronic link	Not recorded	Interpersonal	Website
276	Discussion-personal	Not recorded	Interpersonal	Website
277	Information-electronic link	Not recorded	Interpersonal	Website
278	Information-electronic link	Not recorded	Interpersonal	Website
279	Information-electronic link	Not recorded	Patient Perspective	Website
280	Information-physical copy	Not recorded	Patient Perspective	Website

281	Information-physical copy	Not recorded	Patient Perspective	Website
282	Information-physical copy	Not recorded	Patient Perspective	Website
283	Information-electronic link	Not recorded	Patient Perspective	Website
284	Information-electronic link	Not recorded	Patient Perspective	Website
285	Information-electronic link	Not recorded	Patient Perspective	Website
286	Discussion-forum	Not recorded	Patient Perspective	Website

ID	Audience Type	Audience Sub-type	Interactive Content	Social Media
100	Patient Circle	Other or unspecified	0	Other public service
101	Patient Circle	Other or unspecified	0	Other public service
102	Patient Circle	Parent/Caregiver	0	Other public service
103	Patient Circle	Parent/Caregiver	0	Other public service
104	Patient Circle	Other or unspecified	0	Other public service
105	Patient Circle	Other or unspecified	0	Other public service
106	Patient Circle	Other or unspecified	0	Other public service
107	Patient Circle	Other or unspecified	0	Other public service
108	Patient Circle	Other or unspecified	0	Other public service
109	Patient Circle	Other or unspecified	0	Other public service

110	Patient Circle	Other or unspecified	0	Other public service
111	Patient Circle	Other or unspecified	0	Other public service
112	Patient Circle	Other or unspecified	0	Other public service
113	Patient Circle	Other or unspecified	0	Other public service
114	Patient Circle	Other or unspecified	0	Other public service
115	Patient Circle	Other or unspecified	0	Other public service
116	Patient Circle	Other or unspecified	0	Other public service
117	Patient Circle	Other or unspecified	0	Other public service
118	Patient Circle	Other or unspecified	0	Other public service
119	Patient	Child	0	Other public service
120	Patient Circle	Other or unspecified	0	Other private service
121	Patient Circle	Other or unspecified	0	Other private service
122	Patient Circle	Other or unspecified	0	Other private service
123	Patient Circle	Other or unspecified	0	Other private service
124	Patient Circle	Other or unspecified	0	Other private service
125	Patient Circle	Other or unspecified	0	Other private service
126	Patient Circle	Other or unspecified	0	Other private service
127	Patient Circle	Other or unspecified	0	Other private service
128	Patient Circle	Other or unspecified	0	Other private service
129	Patient Circle	Other or unspecified	0	Other private service
130	Patient Circle	Other or unspecified	0	Other private service
131	Patient Circle	Other or unspecified	0	Other private service
132	Patient Circle	Other or unspecified	0	Other private service
133	Patient Circle	Other or unspecified	0	Other private service

134	Patient Circle	Other or unspecified	0	Other private service
135	Patient Circle	Parent/Caregiver	0	Other public service
136	Patient Circle	Parent/Caregiver	0	Other public service
137	Patient Circle	Parent/Caregiver	0	Other public service
138	Patient Circle	Parent/Caregiver	0	Other public service
139	Patient Circle	Parent/Caregiver	0	Other public service
140	Patient	Child	0	Other private service
141	Patient Circle	Parent/Caregiver	0	Other public service
142	Patient	Child	0	Other private service
143	Patient	Child	0	Other private service
144	Patient	Child	0	Other private service
145	Patient	Child	0	Other private service
146	Patient	Child	0	Other private service
147	Patient Circle	Other or unspecified	0	Other private service
148	Patient Circle	Other or unspecified	0	Other private service
149	Patient Circle	Other or unspecified	1	Facebook
150	Patient Circle	Other or unspecified	1	Other private service
151	Patient Circle	Other or unspecified	1	Other private service
152	Patient Circle	Other or unspecified	1	Instagram
153	Patient Circle	Other or unspecified	1	Twitter
154	Professional	Medical provider	1	Twitter
155	Professional	Medical provider	0	Other private service
156	Patient	Other or unspecified	0	Other private service
157	Patient	Other or unspecified	0	Other private service

158	Professional	Medical provider	1	Other private service
159	Patient Circle	Parent/Caregiver	0	Other public service
160	Patient	Other or unspecified	1	Other public service
161	Patient Circle	Parent/Caregiver	0	Other public service
162	Patient Circle	Parent/Caregiver	1	Other private service
163	Patient Circle	Parent/Caregiver	1	Other private service
164	Patient	Other or unspecified	0	Other private service
165	Patient	Child	0	Other private service
166	Patient	Child	0	Other private service
167	Patient	Child	0	Other private service
168	Professional	Medical provider	0	Other public service
169	Patient	Teen	0	Other private service
170	Patient	Child	0	Other private service
171	Patient	Child	0	Other private service
172	Professional	Medical provider	0	Other public service
173	Patient Circle	Child	0	Other public service
174	Patient	Teen	0	Other public service
175	Patient	Child	1	Other private service
176	Patient	Child	0	Other private service
177	Patient	Child	0	Other private service
178	Patient	Child	0	Other private service
179	Patient	Child	0	Other private service
180	Patient	Child	0	Other private service
181	Patient Circle	Parent/Caregiver	0	Other private service

182	Patient Circle	Child	0	Other private service
183	Patient Circle	Other or unspecified	1	Other public service
184	Professional	Medical provider	0	Other public service
185	Patient	Parent/Caregiver	1	Facebook
186	Patient Circle	Parent/Caregiver	1	Other public service
187	Patient Circle	Parent/Caregiver	1	Other public service
188	Patient Circle	Parent/Caregiver	0	Other public service
189	Patient	Child	0	Other private service
190	Patient	Child	0	Other private service
191	Patient Circle	Parent/Caregiver	0	Other private service
192	Patient Circle	Parent/Caregiver	1	Other private service
193	Patient Circle	Parent/Caregiver	1	Other private service
194	Patient	Parent/Caregiver	0	Other private service
195	Patient	Parent/Caregiver	0	Other private service
196	Patient	Parent/Caregiver	0	Other private service
197	Patient	Parent/Caregiver	0	Other private service
198	Patient	Child	1	Other private service
199	Patient Circle	Child	1	Other public service
200	Patient Circle	Child	1	Other public service
201	Patient Circle	Child	1	Other public service
202	Patient Circle	Child	1	Other private service
203	Patient Circle	Child	1	Other private service
204	Patient Circle	Other or unspecified	0	Other public service
205	Patient	Child	1	Other private service

206	Patient	Child	0	Other private service
207	Patient	Child	1	Other private service
208	Patient	Teen	0	Other private service
209	Patient	Child	1	Other private service
210	Patient	Child	1	Other private service
211	Patient	Child	1	Other private service
212	Patient Circle	Child	1	Other private service
213	Patient Circle	Child	1	Other private service
214	Patient Circle	Parent/Caregiver	1	Other private service
215	Patient Circle	Parent/Caregiver	1	Other private service
216	Patient Circle	Child	0	Other private service
217	Patient Circle	Teen	0	Other private service
218	Patient Circle	Child	0	Other private service
219	Patient Circle	Parent/Caregiver	0	Other private service
220	Patient Circle	Child	0	Other private service
221	Patient Circle	Child	0	Other private service
222	Patient Circle	Child	0	Other private service
223	Patient Circle	Child	0	Other private service
224	Patient Circle	Child	0	Other private service
225	Patient Circle	Child	0	Other private service
226	Patient Circle	Child	0	Other private service
227	Patient Circle	Child	0	Other private service
228	Patient Circle	Child	0	Other private service
229	Patient Circle	Child	0	Other private service

230	Patient Circle	Parent/Caregiver	0	Other private service
231	Patient Circle	Parent/Caregiver	0	Other private service
232	Professional	Medical provider	0	Other public service
233	Patient Circle	Parent/Caregiver	1	Other public service
234	Patient Circle	Child	1	Other private service
235	Patient Circle	Parent/Caregiver	1	Other public service
236	Patient Circle	Child	0	Other private service
237	Patient Circle	Parent/Caregiver	1	Other public service
238	Professional	Medical provider	0	Other public service
239	Patient	Child	0	Other private service
240	Patient	Child	0	Other private service
241	Patient	Child	0	Other private service
242	Patient	Child	0	Other private service
243	Patient	Child	0	Other private service
244	Patient	Child	0	Other private service
245	Patient	Child	0	Other private service
246	Patient Circle	Child	0	Other public service
247	Patient	Parent/Caregiver	0	Other private service
248	Patient	Child	0	Other private service
249	Professional	Medical provider	0	Other public service
250	Patient	Child	0	Other private service
251	Professional	Medical provider	0	Other public service
252	Patient	Teen	0	Other private service
253	Patient	Child	0	Other private service

254	Patient Circle	Parent/Caregiver	1	Other public service
255	Patient Circle	Friend/Community	1	Facebook
256	Patient Circle	Friend/Community	1	Facebook
257	Patient Circle	Friend/Community	1	Facebook
258	Patient Circle	Friend/Community	1	Facebook
259	Patient Circle	Friend/Community	1	Facebook
260	Patient Circle	Friend/Community	1	Facebook
261	Patient Circle	Friend/Community	1	Facebook
262	Patient Circle	Friend/Community	1	Facebook
263	Patient Circle	Friend/Community	1	Facebook
264	Patient Circle	Friend/Community	1	Facebook
265	Patient Circle	Friend/Community	1	Facebook
266	Patient Circle	Friend/Community	1	Other public service
267	Patient	Child	0	Other private service
268	Patient Circle	Sibling	1	Other private service
269	Patient Circle	Parent/Caregiver	0	Other private service
270	Patient Circle	Parent/Caregiver	0	Other private service
271	Professional	Parent/Caregiver	0	Other private service
272	Patient	Parent/Caregiver	0	Other private service
273	Patient Circle	Child	0	Other public service
274	Patient Circle	Parent/Caregiver	0	Other public service
275	Patient Circle	Child	0	Other public service
276	Patient Circle	Other or unspecified	0	Other public service
277	Patient Circle	Other or unspecified	0	Other public service

278	Patient Circle	Parent/Caregiver	0	Other public service
279	Patient Circle	Parent/Caregiver	0	Other private service
280	Patient Circle	Parent/Caregiver	0	Other private service
281	Patient Circle	Parent/Caregiver	0	Other private service
282	Patient Circle	Parent/Caregiver	0	Other private service
283	Patient Circle	Parent/Caregiver	0	Other public service
284	Patient Circle	Parent/Caregiver	0	Other public service
285	Patient Circle	Parent/Caregiver	0	Other public service
286	Patient Circle	Parent/Caregiver	1	Other private service

ID	Perspective	Content Provider	Moderated or Facilitated Content	Login
100	Person	Personal	1	0
101	Person	Personal	1	0
102	Person	Personal	1	0
103	Person	Personal	1	0
104	Person	Personal	0	1
105	Person	Personal	0	1
106	Person	Personal	0	1
107	Person	Personal	0	1
108	Person	Personal	0	1
109	Person	Personal	0	1
110	Person	Personal	0	1

111	Person	Personal	0	1
112	Person	Personal	0	1
113	Person	Personal	0	1
114	Person	Personal	0	1
115	Person	Personal	0	1
116	Person	Personal	0	1
117	Person	Personal	0	1
118	Person	Personal	0	1
119	Person	Personal	0	0
120	Person	Personal	1	0
121	Person	Personal	1	0
122	Person	Personal	1	0
123	Person	Personal	1	0
124	Person	Personal	1	0
125	Person	Personal	1	0
126	Person	Personal	1	0
127	Person	Personal	1	0
128	Person	Personal	1	0
129	Person	Personal	1	0
130	Person	Personal	1	0
131	Person	Personal	1	0
132	Person	Personal	1	0
133	Person	Personal	1	0
134	Person	Personal	1	0

135	Person	Personal	1	0
136	Person	Personal	1	0
137	Person	Personal	1	0
138	Person	Personal	1	0
139	Person	Personal	1	0
140	Organization	Professional	1	0
141	Organization	Professional	1	0
142	Organization	Professional	1	0
143	Organization	Professional	1	0
144	Organization	Professional	1	0
145	Organization	Professional	1	0
146	Organization	Professional	1	0
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148	Person	Personal	1	0
149	Person	Professional	1	0
150	Person	Professional	1	0
151	Person	Professional	1	0
152	Person	Professional	1	0
153	Person	Professional	1	0
154	Person	Professional	1	0
155	Organization	Professional	1	0
156	Organization	Professional	1	0
157	Organization	Professional	1	0
158	Organization	Professional	1	0

159	Person	Personal	0	0
160	Person	Personal	0	0
161	Organization	Professional	1	0
162	Person	Personal	0	1
163	Person	Personal	0	1
164	Person	Professional	1	0
165	Person	Professional	1	0
166	Person	Professional	1	0
167	Person	Professional	1	0
168	Organization	Professional	1	0
169	Person	Professional	1	0
170	Person	Professional	1	0
171	Person	Professional	1	0
172	Organization	Professional	1	0
173	Person	Professional	1	0
174	Person	Professional	1	0
175	Person	Personal	1	0
176	Person	Professional	1	0
177	Person	Professional	1	0
178	Person	Professional	1	0
179	Person	Professional	1	0
180	Person	Professional	1	0
181	Person	Professional	1	0
182	Person	Personal	1	0

183	Organization	Professional	1	0
184	Organization	Professional	1	0
185	Person	Personal	1	0
186	Organization	Personal	1	0
187	Organization	Personal	1	0
188	Organization	Personal	1	0
189	Person	Professional	1	0
190	Person	Professional	1	0
191	Person	Professional	1	0
192	Person	Professional	1	1
193	Person	Professional	1	1
194	Organization	Personal	1	0
195	Organization	Personal	1	0
196	Organization	Personal	1	0
197	Organization	Personal	1	0
198	Person	Personal	1	0
199	Organization	Professional	1	0
200	Organization	Professional	1	0
201	Organization	Professional	1	0
202	Organization	Professional	1	0
203	Organization	Professional	1	0
204	Organization	Professional	1	0
205	Person	Professional	1	0
206	Person	Professional	1	0

207	Person	Personal	1	0
208	Person	Professional	1	0
209	Person	Professional	1	0
210	Person	Professional	1	0
211	Person	Professional	1	0
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213	Person	Professional	1	0
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227	Person	Professional	1	0
228	Person	Professional	1	0
229	Person	Professional	1	0
230	Person	Professional	1	0

231	Person	Professional	1	0
232	Organization	Professional	1	0
233	Person	Professional	1	0
234	Person	Professional	1	0
235	Person	Professional	1	0
236	Person	Personal	1	0
237	Person	Personal	1	0
238	Organization	Professional	1	0
239	Person	Professional	1	0
240	Person	Professional	1	0
241	Person	Personal	1	0
242	Person	Personal	1	0
243	Person	Personal	1	0
244	Person	Personal	1	0
245	Person	Personal	1	0
246	Person	Personal	1	0
247	Person	Personal	1	0
248	Person	Personal	1	0
249	Organization	Professional	1	0
250	Organization	Professional	1	0
251	Organization	Professional	1	0
252	Person	Professional	1	0
253	Person	Professional	1	0
254	Person	Personal	0	1

255	Organization	Personal	1	0
256	Organization	Personal	1	0
257	Organization	Personal	1	0
258	Organization	Personal	1	0
259	Organization	Personal	1	0
260	Organization	Personal	1	0
261	Organization	Personal	1	0
262	Organization	Personal	1	0
263	Organization	Personal	1	0
264	Organization	Personal	1	0
265	Organization	Personal	1	0
266	Person	Personal	1	1
267	Person	Personal	1	0
268	Person	Personal	1	1
269	Person	Personal	1	0
270	Person	Personal	1	0
271	Person	Personal	1	0
272	Person	Personal	1	0
273	Organization	Professional	1	0
274	Person	Professional	1	0
275	Person	Professional	1	0
276	Person	Professional	1	0
277	Organization	Professional	1	0
278	Organization	Professional	1	0

279	Person	Personal	1	0
280	Person	Personal	1	0
281	Person	Personal	1	0
282	Person	Personal	1	0
283	Person	Personal	1	0
284	Person	Personal	1	0
285	Person	Personal	1	0
286	Person	Personal	1	0

Appendix G: Case Study Data Collection

CASE ID	Organizations	Type
1	American Childhood Cancer Organization	Not-for-Profit
2	Robert H. Lurie Comprehensive Cancer Center	Medical
3	Sidney Kimmel Comprehensive Cancer Center	Medical
4	ASK Childhood Cancer Foundation	Not-for-Profit
5	Sidney Kimmel Cancer Center at Thomas Jefferson University	Medical
6	Memorial Sloan-Kettering Cancer Center	Medical
7	Roswell Park Comprehensive Cancer Center	Medical
8	City of Hope Comprehensive Cancer Center	Medical
9	UC Davis Comprehensive Cancer Center	Medical
10	Alex's Lemonade Stand Foundation	Not-for-Profit
11	Children’s Brain Tumor Foundation	Not-for-Profit
12	CancerCare	Not-for-Profit
13	The National Children's Cancer Society	Not-for-Profit

Coding ‘1’ indicates a link to the social media is present on the organization website.

CASE ID	Facebook	Twitter	Instagram	YouTube	LinkedIn	Private	Proprietary	Pinterest	Google+	Flickr	Weibo	Zoom	Inspire.com
1	1	1	1	1				1	1				1
2	1	1	1	1									
3	1	1	1	1							1		
4	1	1	1	1						1			
5	1	1	1		1								
6	1	1	1	1	1		1						
7	1	1	1	1	1		1	1					
8	1	1	1		1	1							
9	1	1	1	1	1	1		1					
10	1	1	1	1	1	1	1	1					
11	1	1				1			1			1	
12	1	1	1	1	1	1							
13	1	1	1				1						
Count	**13**	**13**	**12**	**9**	**7**	**5**	**4**	**4**	**2**	**1**	**1**	**1**	**1**

Appendix H: Case ID 1 Visualization Download

CASE ID 1:
American Childhood Cancer Organization

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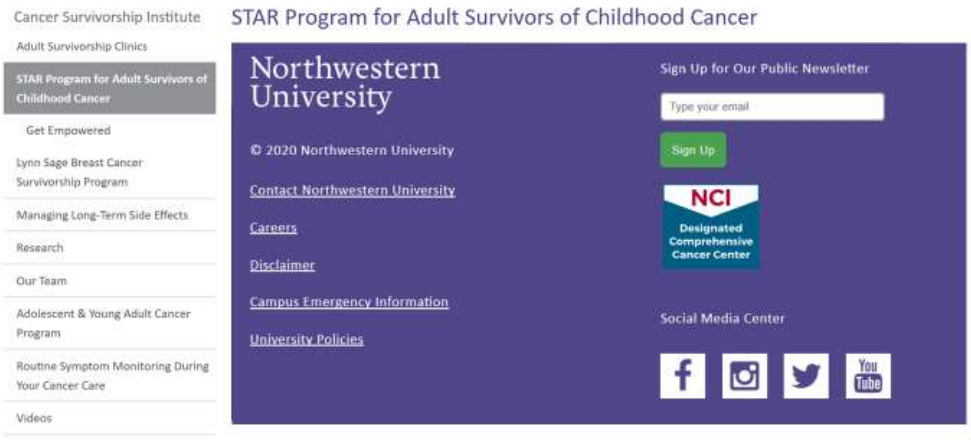
Appendix I: Case ID 2 Visualization Download

CASE ID 2:
Robert H. Lurie Comprehensive Cancer Center



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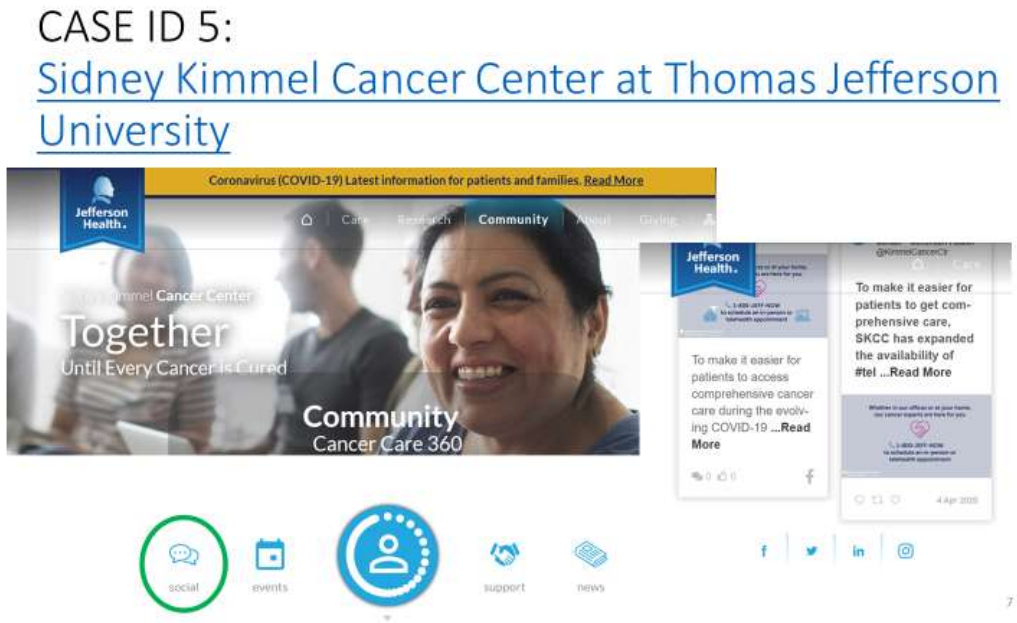
Appendix J: Case ID 3 Visualization Download

CASE ID 3:
Sidney Kimmel Comprehensive Cancer Center

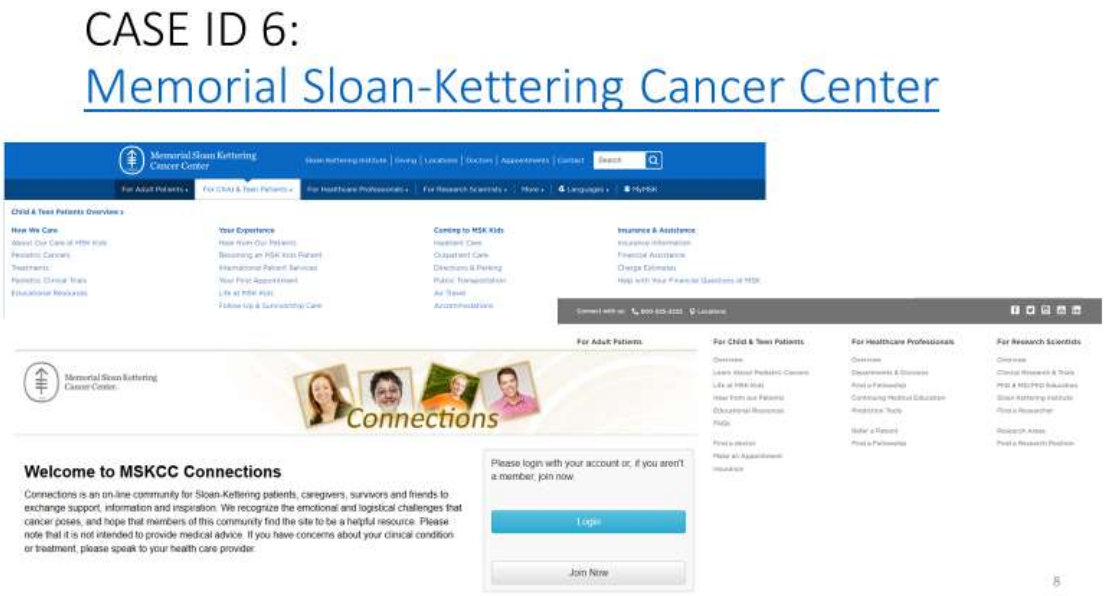
Appendix K: Case ID 4 Visualization Download

CASE ID 4:
ASK Childhood Cancer Foundation

Appendix L: Case ID 5 Visualization Download

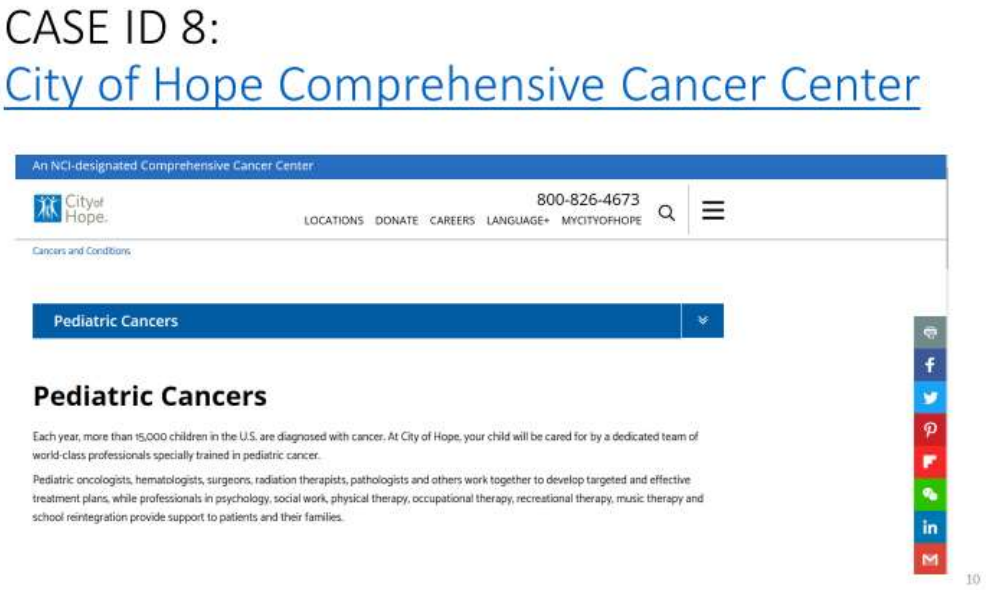


Appendix M: Case ID 6 Visualization Download



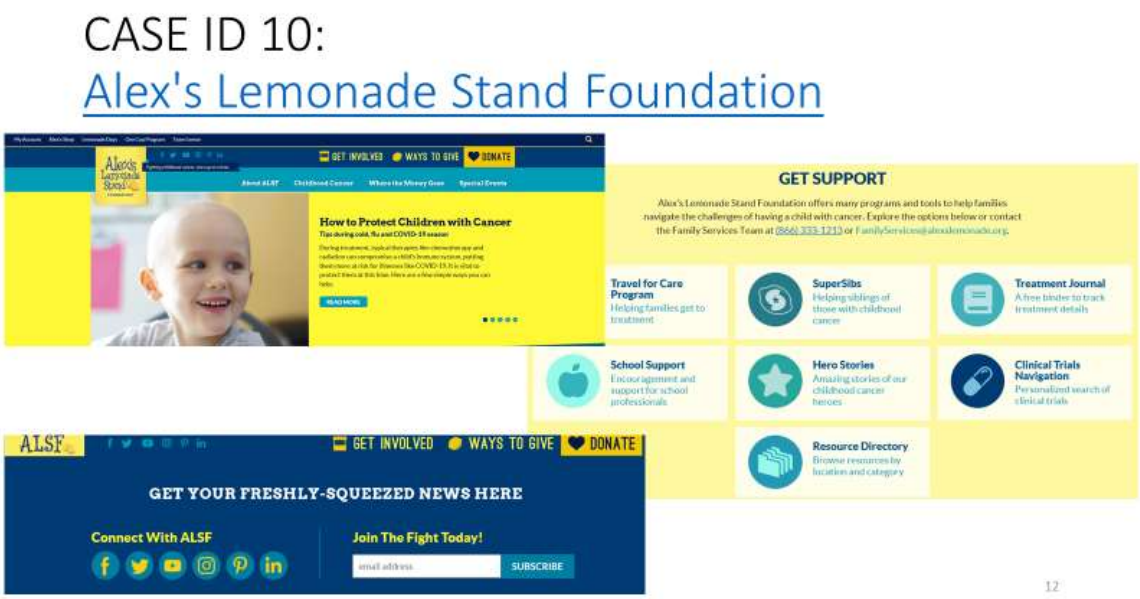
Appendix N: Case ID 7 Visualization Download

Appendix O: Case ID 8 Visualization Download



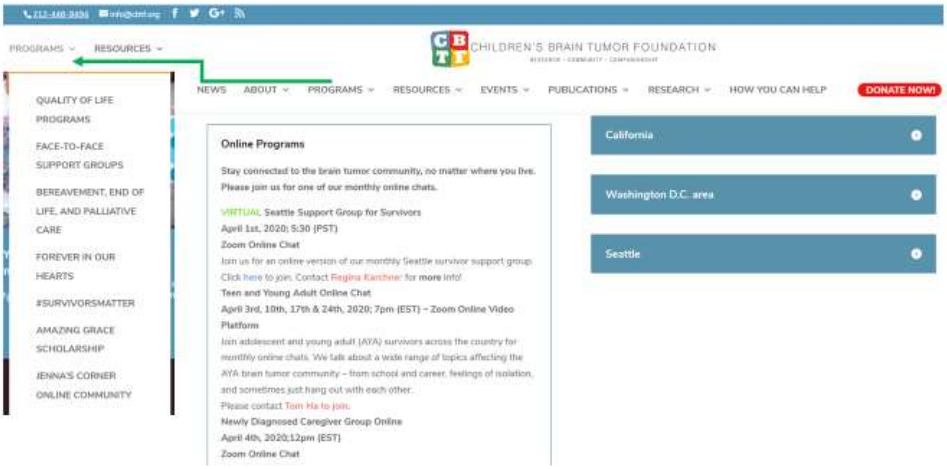
Appendix P: Case ID 9 Visualization Download

Appendix Q: Case ID 10 Visualization Download



Appendix R: Case ID 11 Visualization Download

CASE ID 11:
Children's Brain Tumor Foundation



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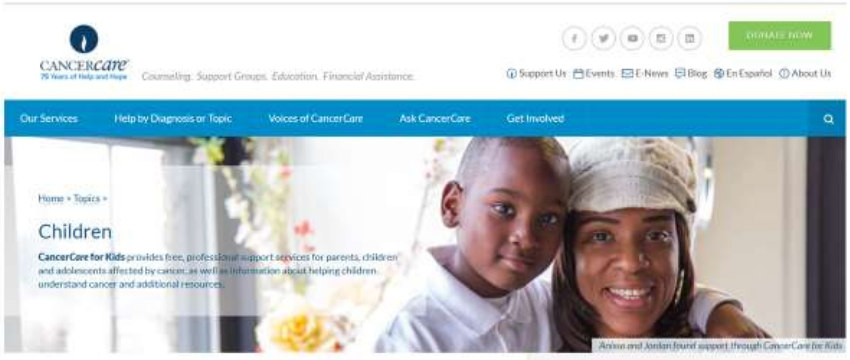
Appendix S: Case ID 12 Visualization Download

CASE ID 12:
Cancer Care



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Appendix T: Case ID 12 Resource List

Case ID 12:
Cancer Care Organization Resource List

American Childhood Cancer Association
855-858-2226, acco.org

Andrew McDonough B+ Foundation
302-563-8389, bepositive.org

Camp Good Days
800-785-2135, campgooddays.org

Camp Kesem
260-225-3736, campkesem.org

Camp Mak-A-Dream
406-549-5987, campdream.org

Camp Quality USA
campqualityusa.org

Cancer Support Community
888-793-9355, cancersupportcommunity.org

Chai Lifeline
212-465-1300, chailifeline.org

Children With Hair Loss
734-379-4400, childrenwithhairloss.us

Children's Organ Transplant Association (COTA)
800-366-2682, cota.org

Compass to Care
773-657-3269, compasstocare.org

Compassion Can't Wait
compassioncantwait.org

Expect Miracles Foundation
617-391-9235, expectmiraclesfoundation.org

Family Reach
familyreach.org

First Hand Foundation
816-201-1569, firsthandfoundation.org

Jack and Jill Late Stage Cancer Foundation
jajf.org

Kids Wish Network
888-918-9004, kidswishnetwork.org

KidsKonnected
800-899-2866, kidskonnected.org

Locks of Love
888-896-1588, locksoflove.org

Make-A-Wish
800-722-9474, wish.org

Miracle Flights
800-359-1711, miracleflights.org

National Children's Cancer Society Beyond the Cure Ambassador Scholarship Program
thenccs.org/scholarship

Pinky Swear Foundation
952-974-9600, pinkyswear.org

Red Dog Foundation
reddogfund.org

Starlight Children's Foundation
310-479-1212, starlight.org

Sunshine Kids
800-594-5756, sunshinekids.org

SuperSibs!
888-417-4704, supersibs.org

The National Children's Cancer Society (NCCS)
314-241-1600, thenccs.org

United HealthCare Foundation
855-698-4233, uhccf.org

Wigs for Kids
440-333-4433, wigsforkids.org

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Appendix U: Case ID 13 Visualization Download

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Create an Account

You must create an account in order to save your results, view previously saved assessments or complete an unfinished one. This will allow you to return at a later date to view your potential late effects, recommended follow-up care and prevention tips. Once your account is created, you will need to sign-in to proceed.

By creating an account, you are accepting our terms and conditions/privacy policy and agreeing to receive e-mail messages when this tool is updated and when there is important information to share about survivorship. If you do not want to receive these e-mail messages uncheck the appropriate box below.

Late Effects Assessment Tool - Registration

Account Type *

Medical Professional
Parent/Guardian
Survivor
Social Worker
Other

SURVIVOR STORIES
CONFERENCES
LONG-TERM FOLLOW UP CLINICS
INFORMATION FOR SURVIVORS
INFORMATION FOR PARENTS
COLLEGE SCHOLARSHIPS
LATE EFFECTS AFTER TREATMENT TOOL

PUBLICATIONS
WEBINARS
HELPFUL RESOURCES
LATE EFFECTS AFTER TREATMENT TOOL
SPECIAL EDUCATION INFORMATION
EDUCATIONAL ARTICLES
CHILDHOOD CANCER FACTS
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